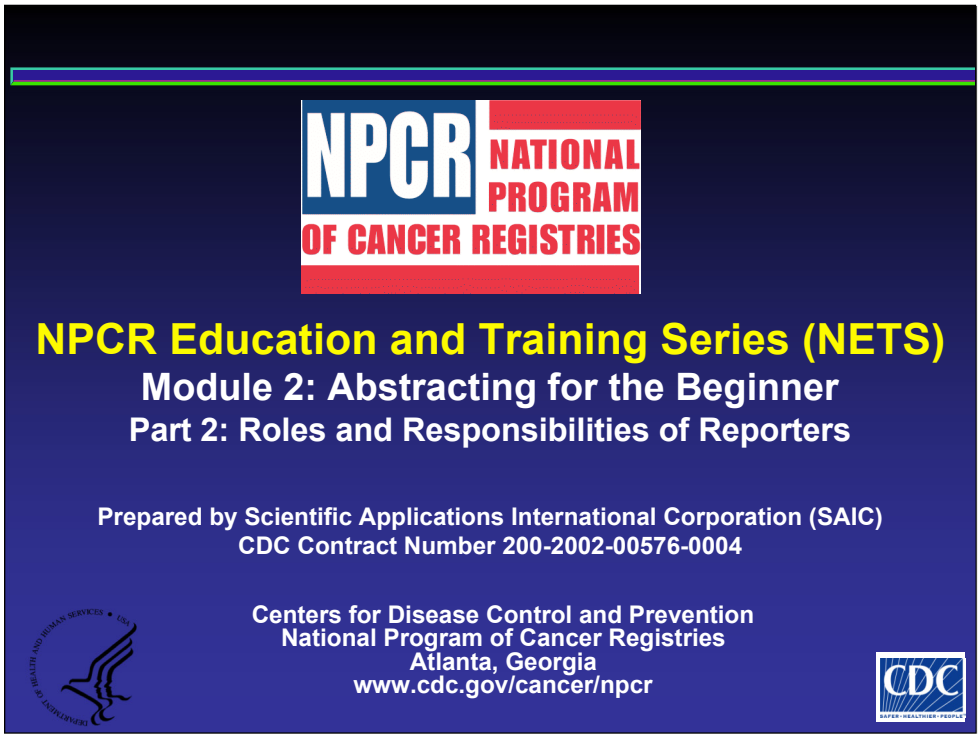
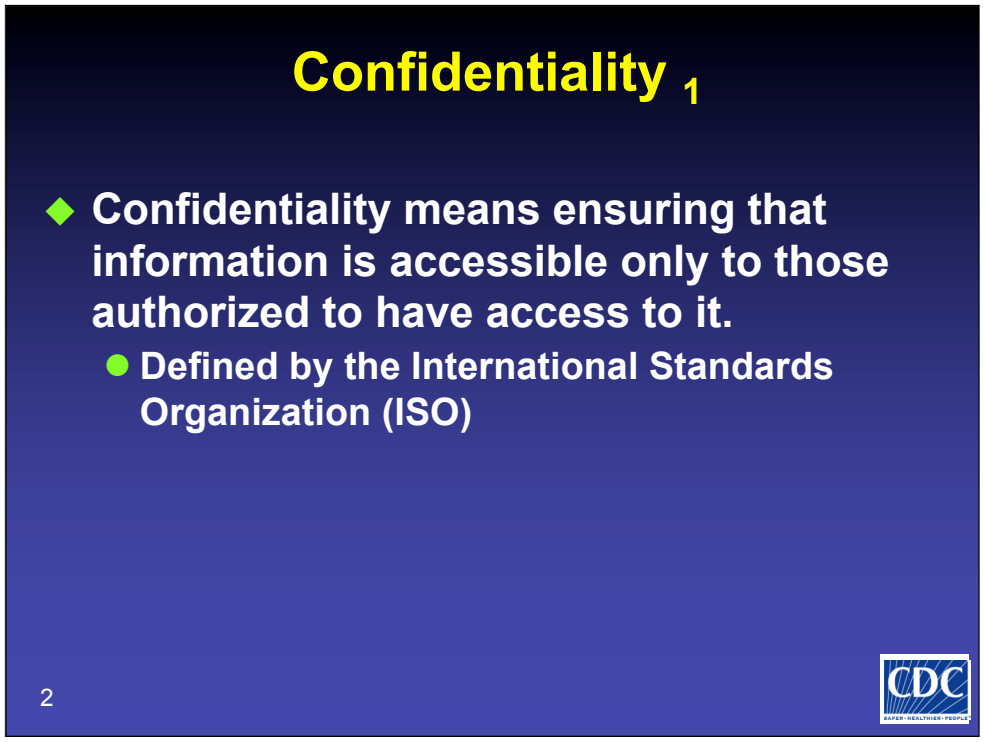
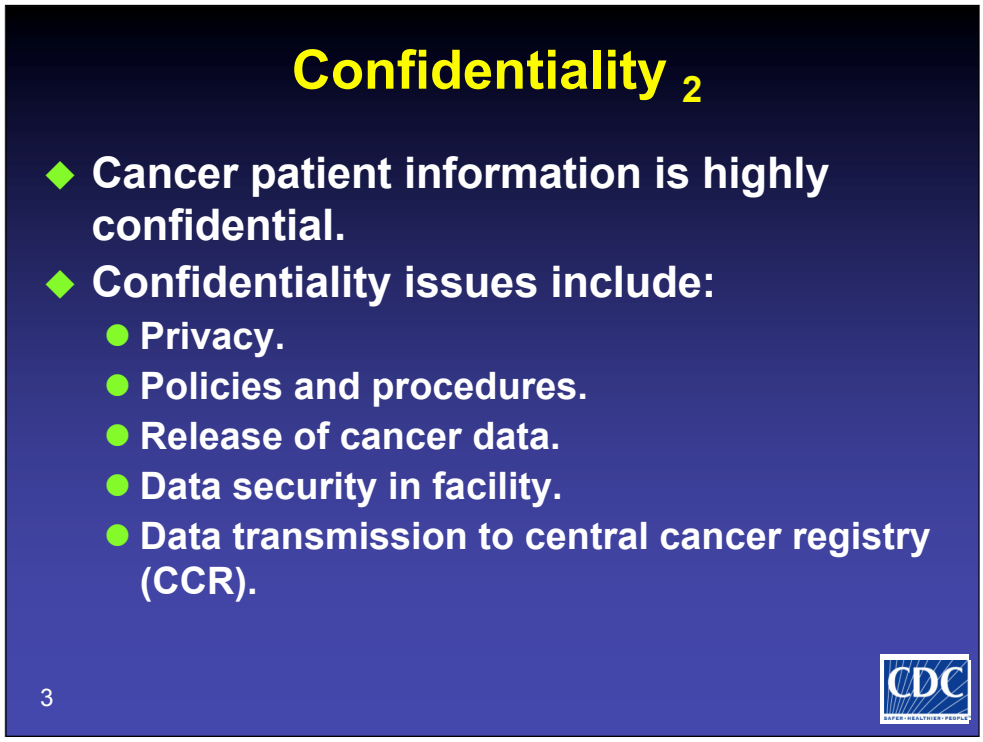


Part 2 of this module describes the roles and responsibilities of cancer data reporters, the materials and references they need, and what is involved in the cancer reporting process.



Cancer data is very personal and highly confidential. It also contains personal identifiers that could be used to perpetrate identity fraud. Confidentiality is defined as making sure that certain information is seen only by people who are authorized to use the information.



A cancer data reporter is responsible for maintaining the confidentiality of cancer patient information. Confidentiality requirements are similar to policies that a medical facility or physician's office must adhere to. It is extremely important to protect the privacy of the patient, physicians, and health care facilities. Policies and procedures must be established to ensure both confidentiality and privacy for all entities.

Any release of cancer registry data should be performed in accordance with written policies and procedures. Appropriate measures must be taken to make cancer data stored at the facility secure from unauthorized viewers. This can be done through password protection, different levels of data access, and locked file cabinets if paper records are kept. Any data transmission must be handled with extreme care whether it is electronic or on paper.

If confidential data are transmitted electronically to the state central cancer registry, the data should be encrypted and password protected through a secure Internet site. If postal mail is used, the package should be securely sealed and marked confidential. Faxing data to a secure fax machine may be a more secure method of transmitting data as long as careful attention is taken to ensure that the phone number used is correct. Both the reporter and the facility can never be too cautious with the security of cancer data.

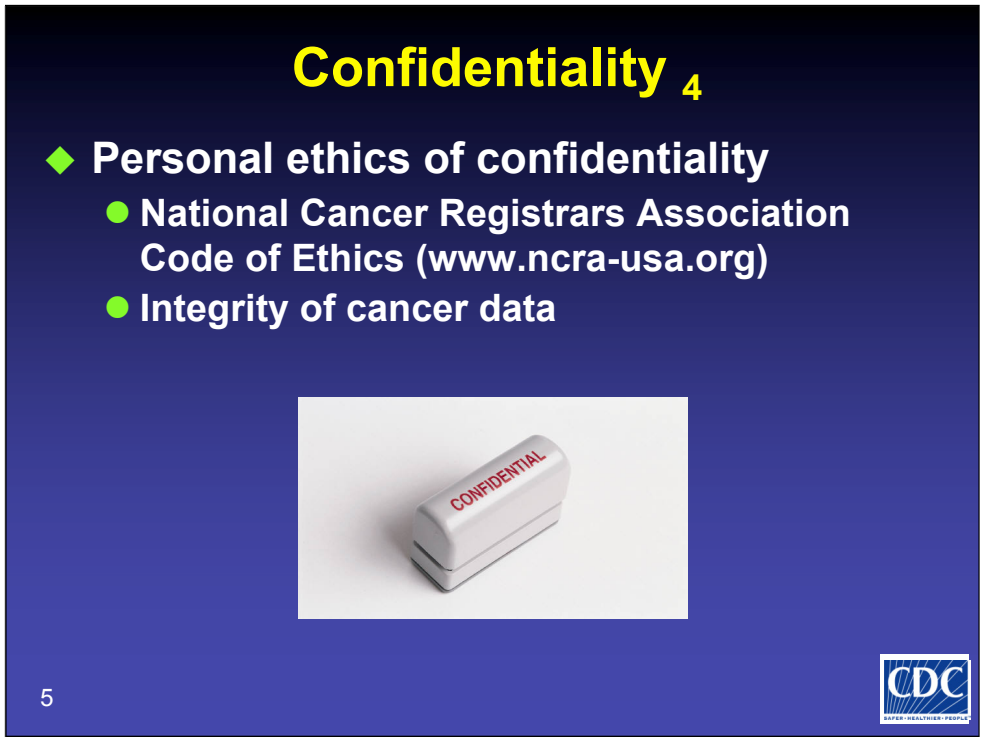
Confidentiality 3

- Health Insurance Portability and Accountability Act (HIPAA)
  - Enacted in 1996
  - Privacy rule enacted April 14, 2003
  - Protects the patient and provider
  - Disclosure without authorization permitted to CCR

4

The Health Insurance Portability and Accountability Act (HIPAA) was actually enacted in 1996, but the privacy rule that affects cancer reporting did not come into effect until April 14, 2003. HIPAA establishes regulations for the use and disclosure of protected health information. This includes any information that can be linked to an individual such as name, address, and social security number. Protected health information is also any information about health status, provision of health care, or payment for health care.

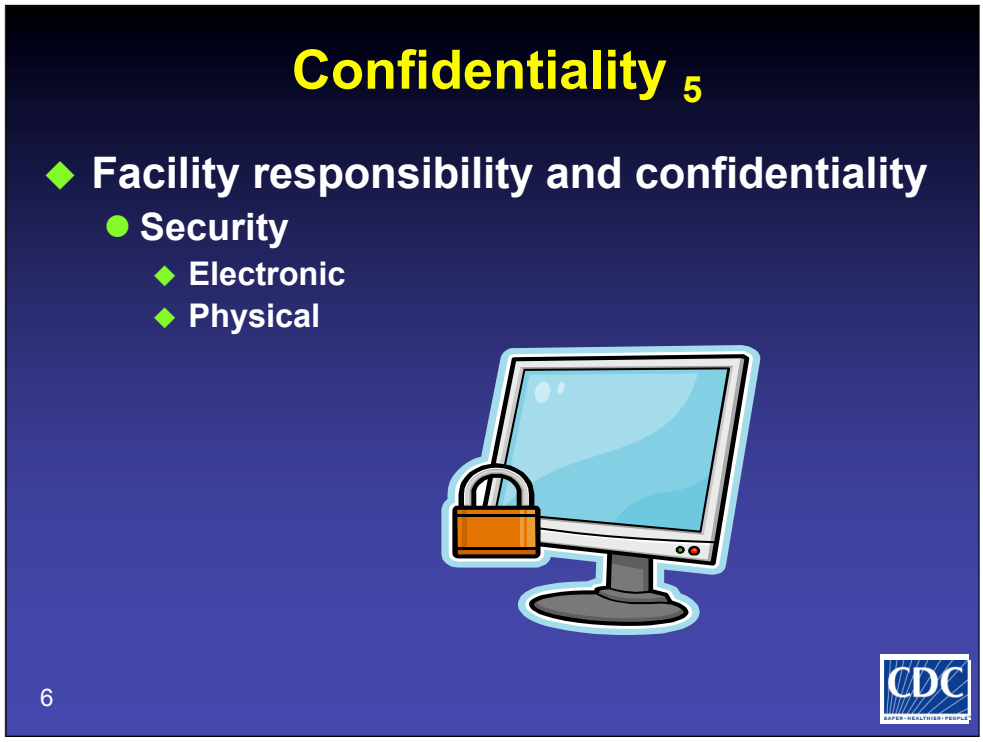
HIPAA allows disclosure of patient data without patient authorization from a healthcare provider to a public health authority. It also allows disclosure of patient data without authorization from one reporter to another if both are providing care to the patient. Thus, facilities that report cancer data to central cancer registries (CCRs) are covered under HIPAA. It is important to discuss the details of data transmission with your CCR and develop your policy and procedures accordingly.



A cancer data reporter must perform his or her duties with the utmost professionalism. The individual must adhere to a code of conduct that ensures the privacy, security and integrity of the cancer data being collected.

The National Cancer Registrars Association adopted a code of ethics for the cancer registry profession that can be viewed on their Web site at www.ncra-usa.org. These same principles should apply to any cancer data reporter.

Reporting facilities may ask the cancer data reporter to sign a confidentiality pledge as part of employment.



The reporting facility is responsible for using whatever means are necessary to secure cancer data. This security encompasses the electronic and physical aspects of maintaining the data. The computer that houses the data should be in a secure area. All computer software should provide a timeout—or suspend—when there has been a period without activity. The reporter should log off when he or she is going to be away from the database for any length of time.

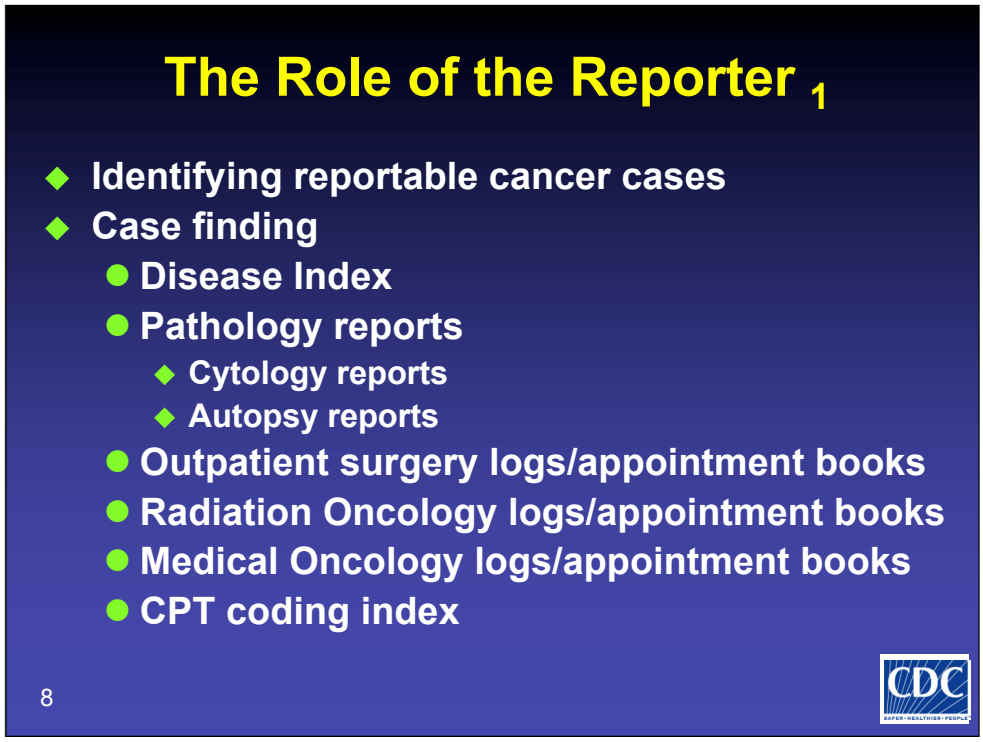
Computer monitor security screens can prevent inadvertent viewing of confidential information displayed on the monitor. Also, if patient medical records are used to abstract data, they must be secured when not in use, and should never be left open on a desk unattended.

Additional security measures are necessary if cancer data are stored on laptops, as they can be removed easily by unauthorized persons.

The reporter is responsible for ensuring data are secure through password protection, encryption, and other means of electronic data security.

The reporting facility may ask the reporter to sign a confidentiality agreement. This agreement usually states that the reporter will not release confidential information to unauthorized persons. The central cancer registry (CCR) will provide a secured means of transmitting the cancer data to them. The policy and procedures of the CCR regarding data transmission should be shared with the reporting facility.

A Business Associates Agreement (BAA) between the CCR and the reporting facility is not necessary because the facility is covered by the Health Insurances Portability and Accountability Act (HIPAA) to report cancer data to the CCR. However, if a facility plans to contract or outsource the reporting of its cancer data, it will want to look into a BAA to maintain patient confidentiality at the highest level. The BAA confirms the individual is performing a function or activity on behalf of a covered entity. The CCR is considered a covered entity under HIPAA, which covers both entities since the health information is being transmitted in electronic format according to HIPAA guidelines. The CCR should have specific policies and procedures relative to HIPAA compliance.



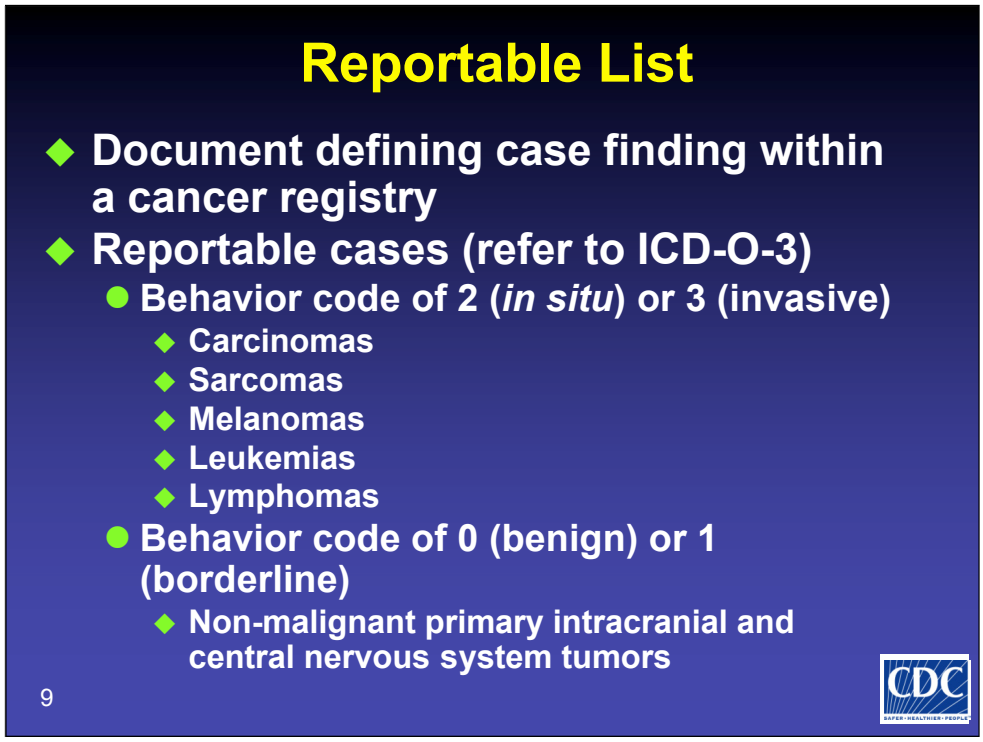
The reporter's responsibility is to identify all reportable cancer cases within the reporting facility and to abstract and transmit them to the central cancer registry (CCR) according to state law.

To do this, the reporter must identify all reportable cancer cases. This can be accomplished by reviewing several sources of cancer cases, and will vary depending on the facility type. Not every facility reporting to the CCR will have all of the sources on this list. Active case finding is the most effective method. Cases can be identified from the disease index in a hospital based on ICD-9 diagnosis codes. For pathology laboratories, this may mean reviewing every pathology or cytology report. Reviewing all reports is essential to ensure complete cancer reporting. Some pathology laboratories may use software with specific diagnosis codes such as SNOMED or ICD-O that can be used to identify reportable cases. However, after these cases are separated, it is important to review each malignant report to ensure it is a reportable case. It is also necessary to review autopsy reports to capture a diagnosis of cancer that may otherwise go undocumented.

It is necessary to review consult logs and appointment books for radiation and medical oncology and other outpatient facilities to capture all reportable cancer cases. Current procedural terminology (CPT) treatment codes can also assist in identifying reportable cancer cases.

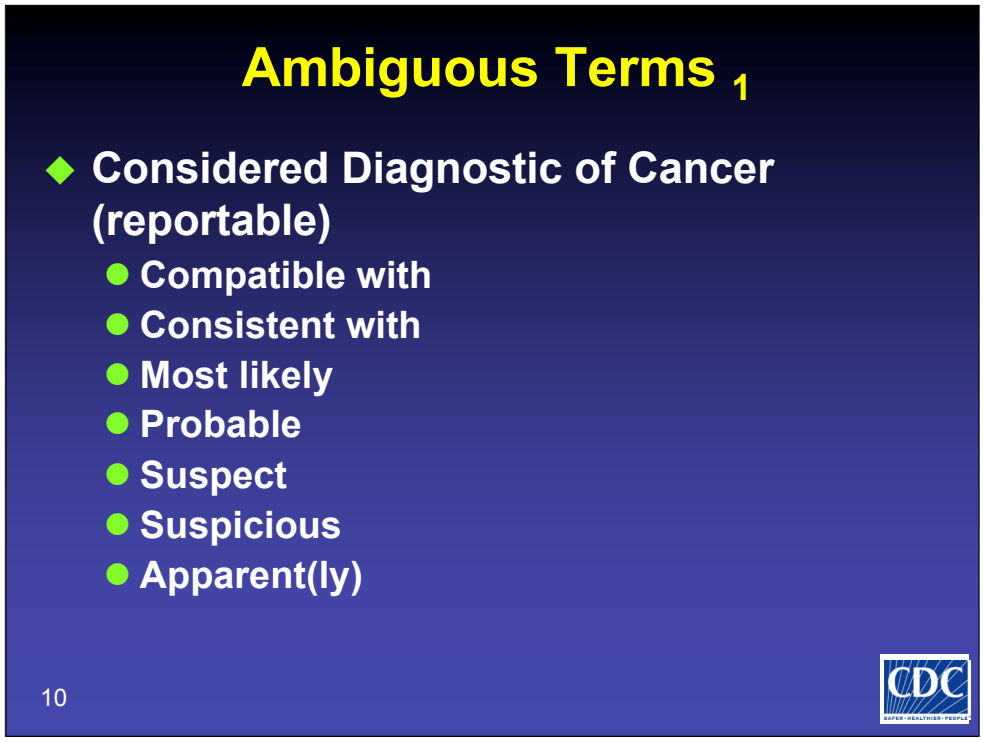
Identification of all source documents is vital for case finding regardless of the reporting facility type.

Passive case finding occurs when the facility relies on someone else to provide the list of reportable cases to be abstracted. A combination of active and passive case finding can be used if the facility cannot support the costs of active case finding alone. After the cases have been identified, a record log or suspense file can be created. Creating a log of reportable cancer cases allows monitoring of case finding methods and ensures that they are effective, efficient,



The reportable list is a list of the types of diseases a facility or central cancer registry (CCR) collects. Common forms of cancer such as carcinomas, sarcomas, melanomas, leukemias, and lymphomas may be easily recognized. All of these are reportable diseases. However, other terms may not be as easily recognized as cancers, such as Hutchinson's melanotic freckle or Queyrat's erythroplasia. To identify the complete list of reportable cancers, you will need to refer to the ICD-O, which has a list of tumors with behavior codes indicating the malignancies and other reportable tumors. Behavior code 2 is an in situ cancer, and behavior code 3 is an invasive cancer.

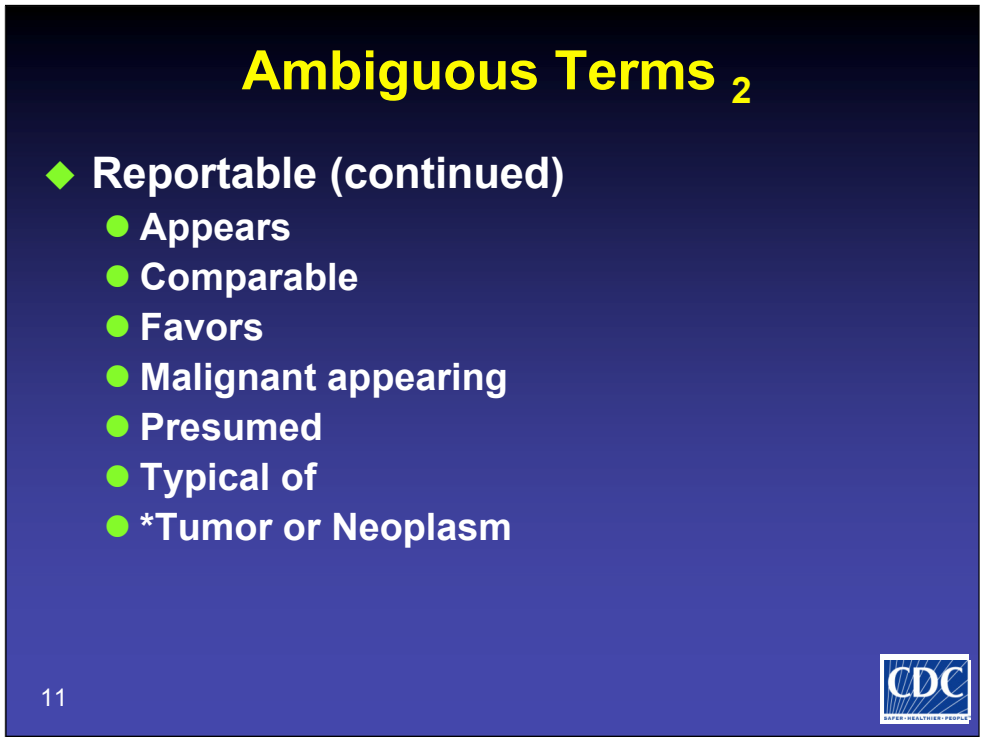
Benign primary intracranial and central nervous system tumors are also reportable. These are tumors with behavior codes of 0 (benign) or 1 (borderline).



Occasionally, physicians are not clear in their statements about a cancer diagnosis and terms can sometimes be vague or ambiguous.

This is a list of terms that are considered diagnostic of cancer. For example, CT of the chest shows a mass in the right upper lobe of the lung consistent with primary malignancy. Several lesions are noted within the left lobe of the liver that are suspicious for metastasis.

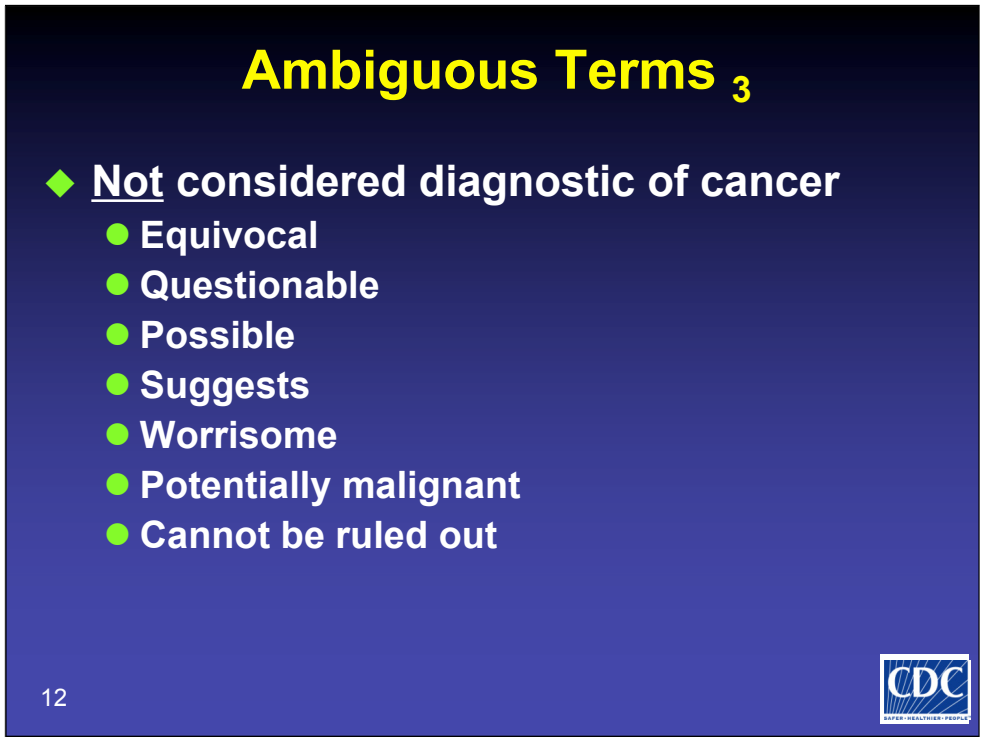
This case would be reportable because the terms “consistent with” and “suspicious” are considered diagnostic of cancer. This case would be reported as a right upper lobe lung primary with liver metastasis. Reference manuals with lists of terms specific to reportability are the SEER coding manual, the FORDS (Facility Oncology Registry Data Standards) manual, and the central cancer registry’s data collection manual.



Here is a list of other reportable terms.

An exception is if cytology is reported as suspicious and there is no positive biopsy or physician statement to support the cytologic findings. This is not considered a diagnosis of cancer.

*The terms "tumor" and "neoplasm" are reportable beginning with 2004 diagnoses for brain and central nervous system tumors (C70.0–C72.9) and pituitary gland, craniopharyngeal duct, and pineal gland tumors (C75.1–C75.3).



These terms are **not** diagnostic of cancer.

For example, a CT of the chest shows a mass in the right upper lobe of the lung reported as "worrisome for malignancy." A biopsy is recommended.

This case would not be added into the database. "Worrisome" is not a term recognized as diagnostic of cancer.

The central cancer registry (CCR) may require facilities to generate an accession register. This is a list of all cases based on the year when they were added to the database. This list is used to monitor case finding and assess the workload of the reporter. It can be used by the CCR to monitor case ascertainment at the facility and determine if case finding is complete. If there is a reduction in the number of cases from one year to the next, the reporter may be asked to review case finding processes for possible missed cases. The accession register is not always required by the CCR, but it is a very good check and balance system between the reporter and the CCR.

Is This Reportable? 1

- **Case A**
  - **1/27/07: CT of the chest: 2cm x 3cm mass in left upper lobe of the lung suspicious for primary malignancy. No evidence of mediastinal lymphadenopathy noted.**

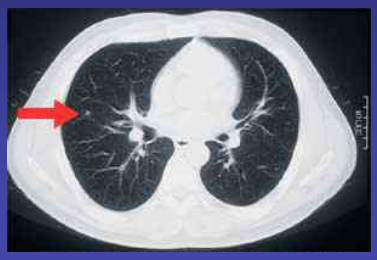


Image source:
http://rad.usuhs.edu/medpix/medpix_image.html?imageid=31261

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Let's take a look at some diagnoses and decide whether the case is reportable.

Case A. On January 27, 2007 a CT of the chest is reported to have a 2cm x 3cm mass in the left upper lobe of the lung suspicious for primary malignancy. No evidence of mediastinal lymphadenopathy is noted.

This case is reportable. The term "suspicious" is recognized as diagnostic of cancer.

Is This Reportable? 2

- Case B
  - 1/29/07: Screening mammogram: 3cm mass noted in the upper outer quadrant of the right breast. Margins irregular and spiculated with some architectural distortion. Possible primary breast cancer. Biopsy recommended.

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Case B. On January 29, 2007, a screening mammogram is reported as having a 3cm mass noted in the upper outer quadrant of the right breast. The margins are irregular and spiculated with some architectural distortion. The final diagnosis is possible primary breast cancer. A biopsy is recommended.

This case is **not** reportable. The term “possible” is not considered diagnostic of cancer, even though the margins are described as irregular and spiculated.

Is This Reportable? 3

- Case C
  - 2/3/07: CT of the abdomen and pelvis: 7cm mass in the lower pole of the right kidney compatible with renal cell carcinoma. There is no evidence of extension of the mass outside of the kidney on imaging

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Case C. On February 3, 2007 a CT of the abdomen and pelvis is reported as having a 7cm mass in the lower pole of the right kidney compatible with renal cell carcinoma. There is no evidence of extension of the mass outside of the kidney on imaging.

Yes, this is a reportable case. The term “compatible with” is recognized as diagnostic of cancer.

Here are some other diagnoses. Are they reportable?

• AIDS is not reportable. AIDS may be associated with particular types of cancer, but AIDS by itself is not reportable.

• Intraductal carcinoma of the breast is reportable. This is an early form of breast cancer.

• Crohn's disease of the colon is not reportable. It is not a malignancy.

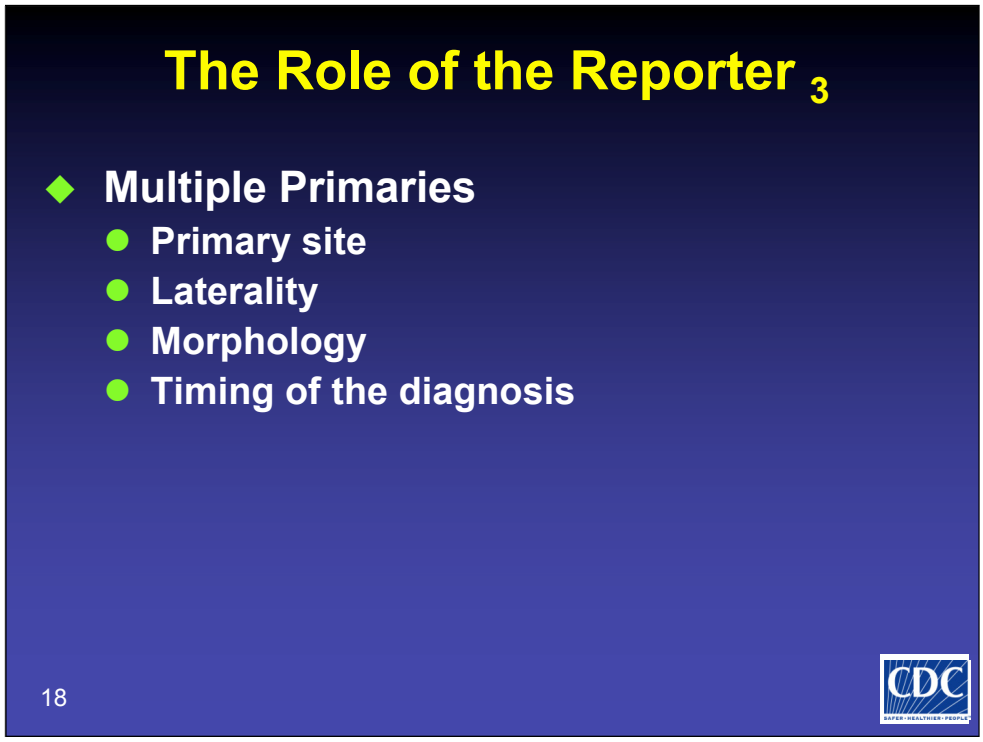
• Malignant melanoma is reportable. It is a form of skin cancer and can be very aggressive.

• Squamous cell carcinoma of the skin is not reportable. Although it is a malignancy, basal cell and squamous cell carcinomas of the skin are not reportable cancers for most central cancer registries (CCRs).

• A brain tumor is reportable. Since January 2004, all benign or malignant tumors of the brain are reportable tumors.

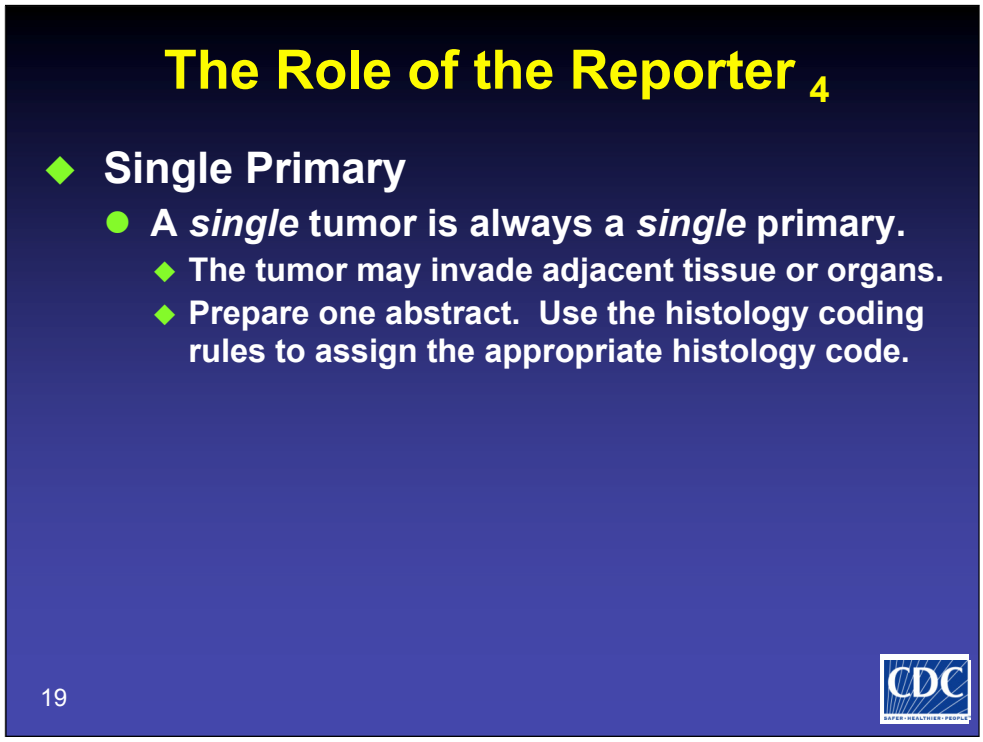
Note: Any benign or malignant disease, although not reportable by standard setters, may be reportable by agreement within your region or state.

Reporters must also be aware of all reportable diagnoses required by the CCR.



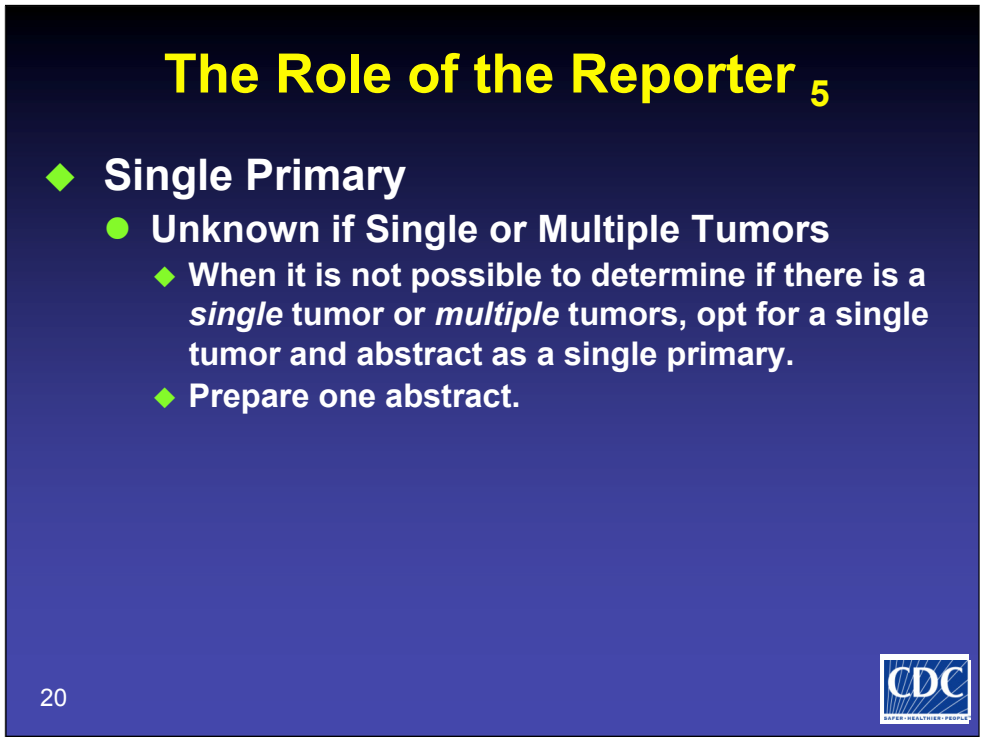
When case finding is performed, the patient may have been identified already as a cancer patient. When this occurs, it must be determined if the reported tumor is a single or multiple primary. To determine if a tumor is a multiple primary, consider the primary site, the laterality, the morphology, and the timing of the diagnosis.

It is important for the reporter to verify the new case is indeed a different primary from any others that may have been reported on that patient. It is necessary to review text within other abstracts to ensure the new case is not a recurrence or metastasis from a previously recorded primary.

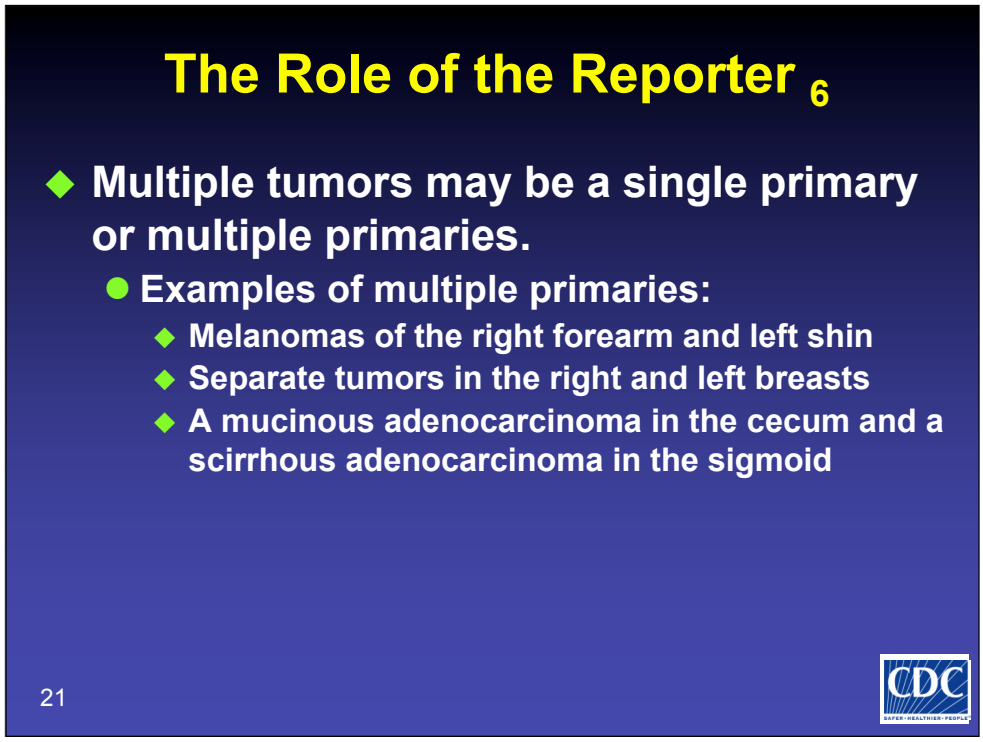


New rules for counting multiple tumors were implemented on January 1, 2007. The central cancer registry can help you determine multiple primaries for difficult cases. The next few slides are an overview of the multiple primaries rules.

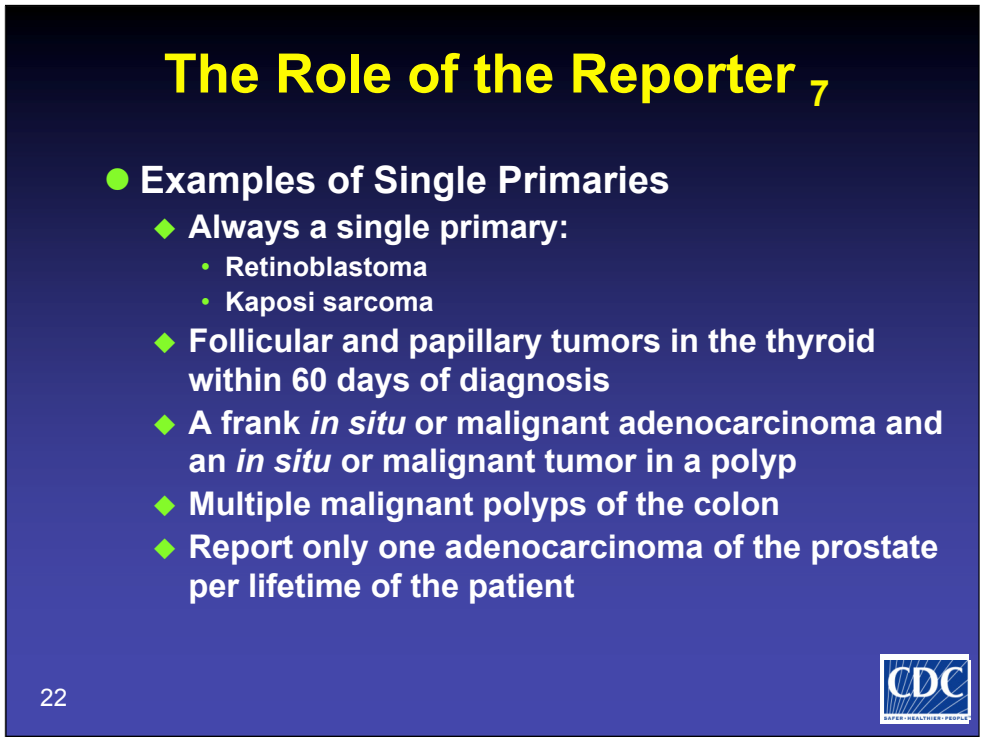
The first rule is that a single tumor is a single primary. This means one abstract is created for the case, regardless of how many sites of metastases the case has.



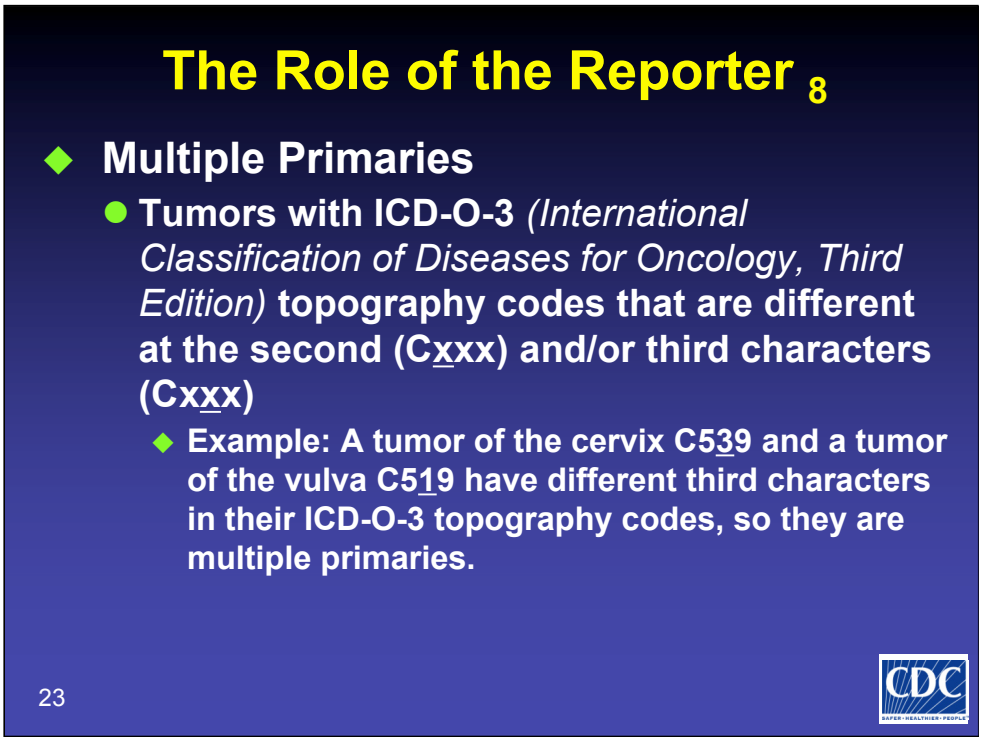
If you can't tell how many primary tumors the patient has, complete only one abstract for the case.



When it appears that the patient has more than one primary tumor, different rules apply for different primary sites. You will need special reference materials for these site-specific rules. This slide shows different scenarios and how the multiple primaries are counted.

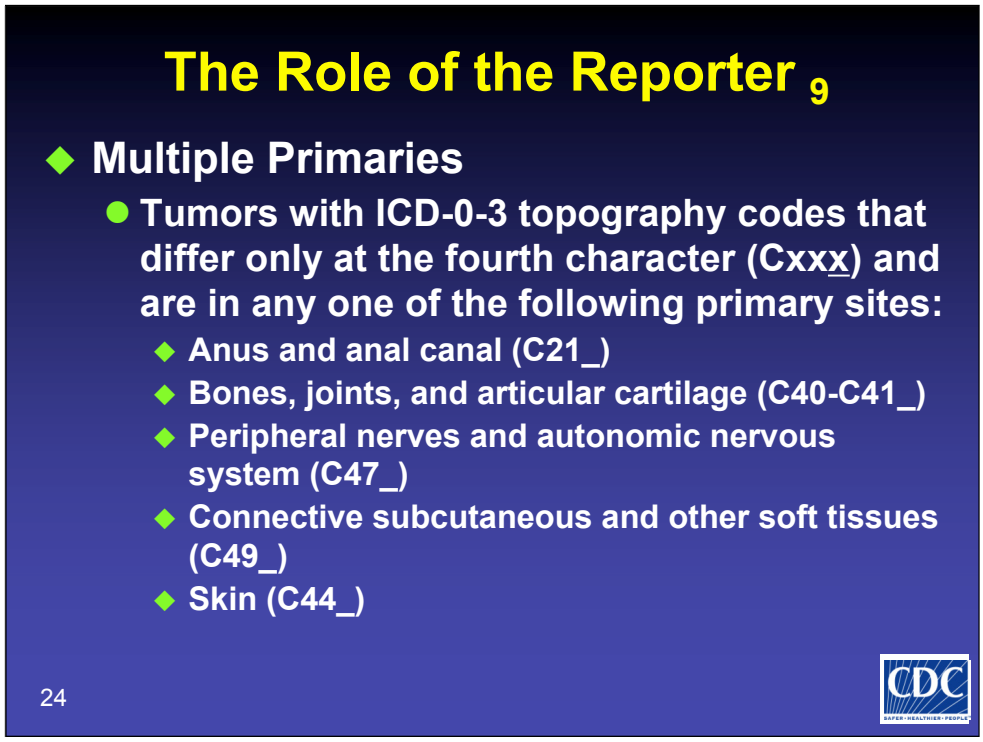


These are examples of multiple tumors reported as a single primary.

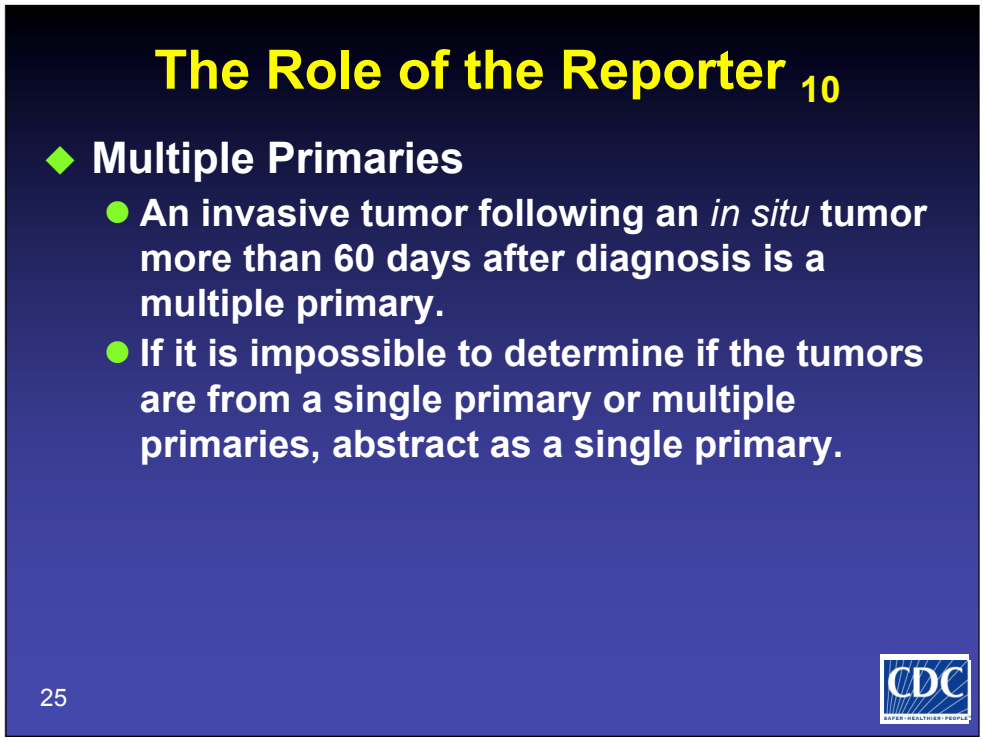


The rules for counting multiple primaries are based on discussions with physicians, pathologists, and central cancer registry experts and epidemiologists. Although the rules may seem complex, they are actually based on common sense and common issues. As previously mentioned, the rules are based on the timing between diagnoses, location of the tumors, cell types, and other factors.

One of the primary rules is that tumors are separate primaries if they are in different organ systems.

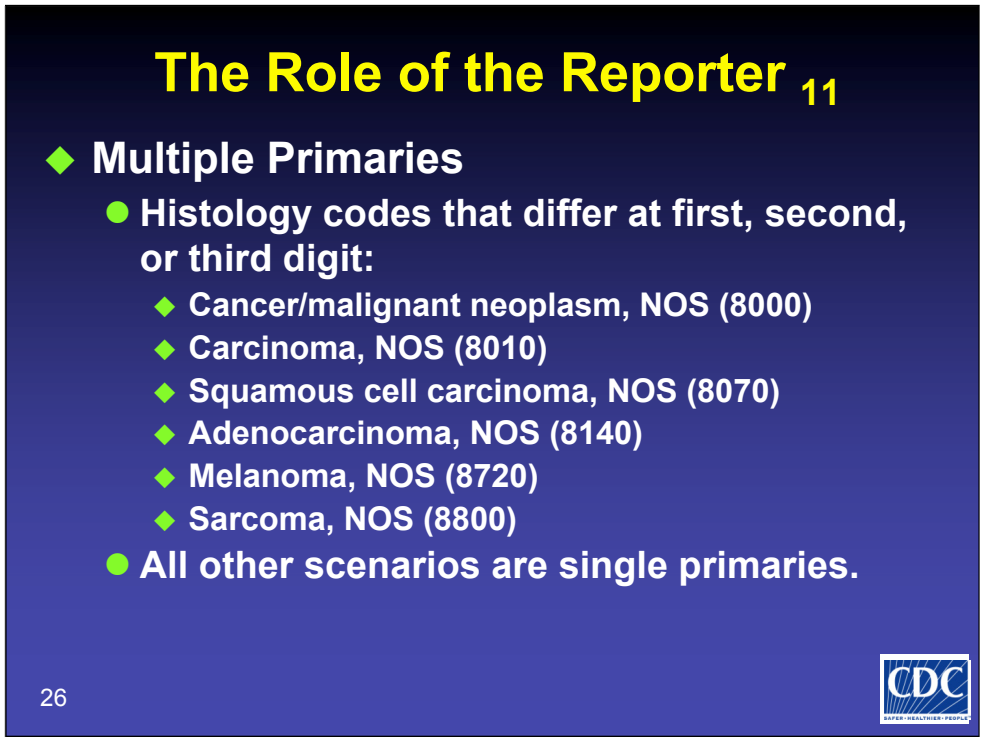


Certain sites have special rules about multiple primaries. For example, the different segments of the colon are counted separately, as are different areas of the skin.



The purpose of these rules is to ensure the case is counted as an invasive cancer case when incidence data that includes only invasive cancer are published. Abstract these cases as multiple primaries even if the managing physician or medical record has a statement indicating it is a recurrence.

When it is impossible to determine if there is a single primary or multiple primaries, abstract as a single primary.



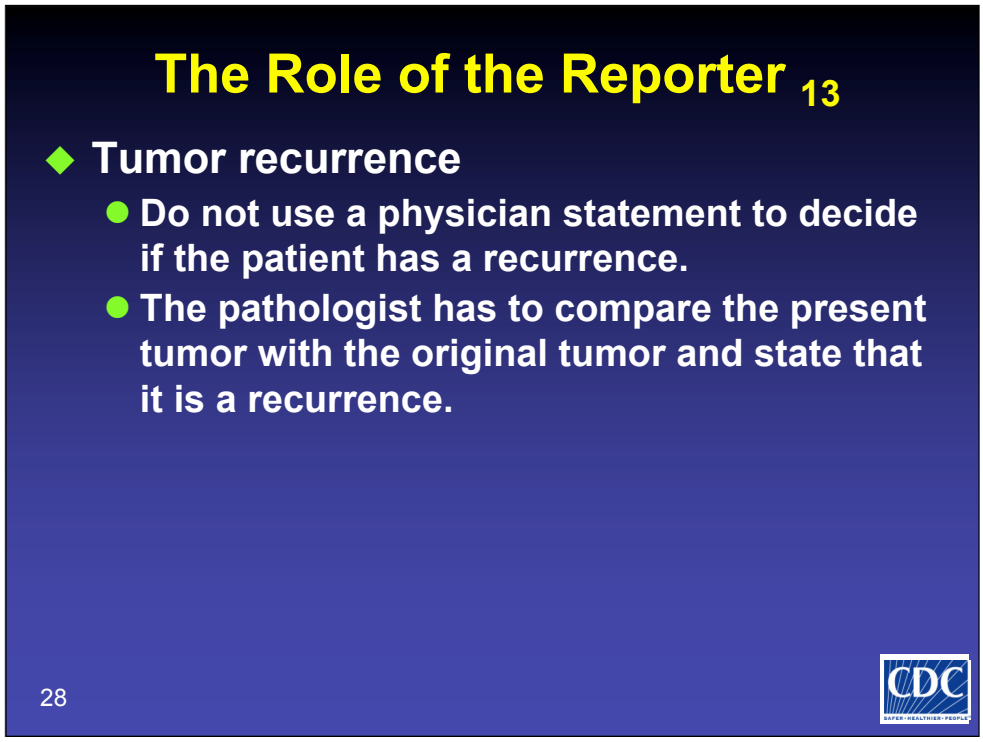
One of the multiple primaries rules deals with different types of cancers in the primary site. These are examples of non-specific, but different, types of cancers.

The default rule is to complete one abstract for any case that doesn't meet any of the criteria for the other rules.

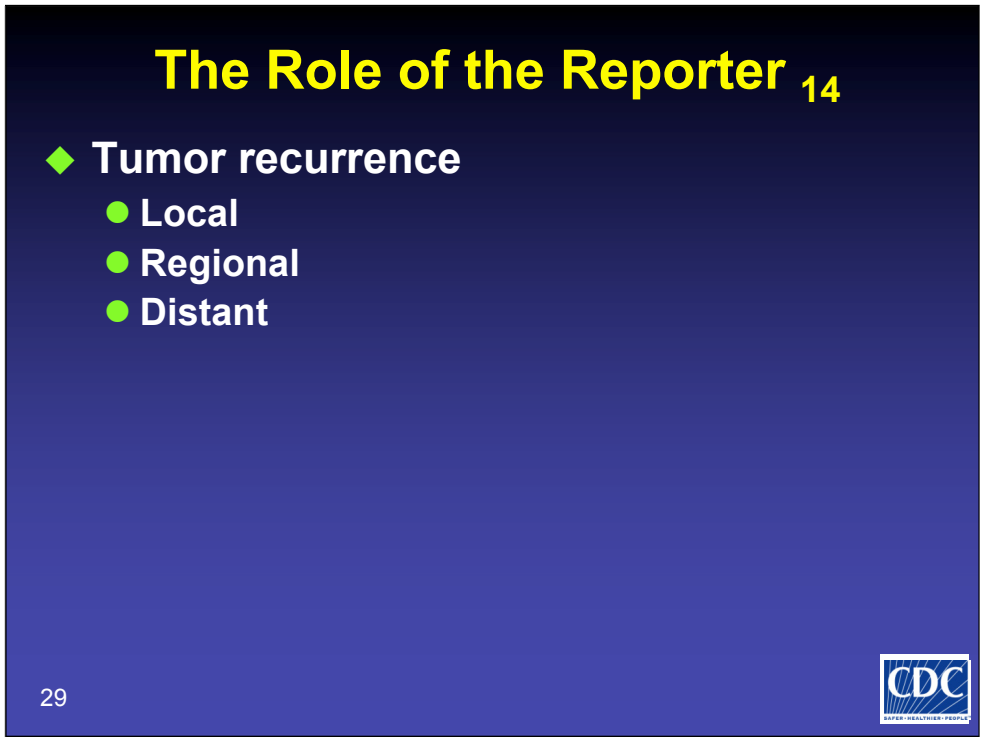
Timing rules vary by primary site. Some sites have one year between diagnoses, and others have three to five years between diagnoses. Some exceptions to the timing rules are listed here.

The following cancers are always considered a continuation of the original disease without time limit; in other words, they are always a single primary.

- Non-malignant primary intracranial and central nervous system tumors within a single site having one histology.
- Bladder primaries with morphology codes 8120–8130.
- Invasive adenocarcinoma of the prostate.
- Kaposi sarcoma of any site.
- Lymphoma and leukemia histologies that are determined to be the same primary.

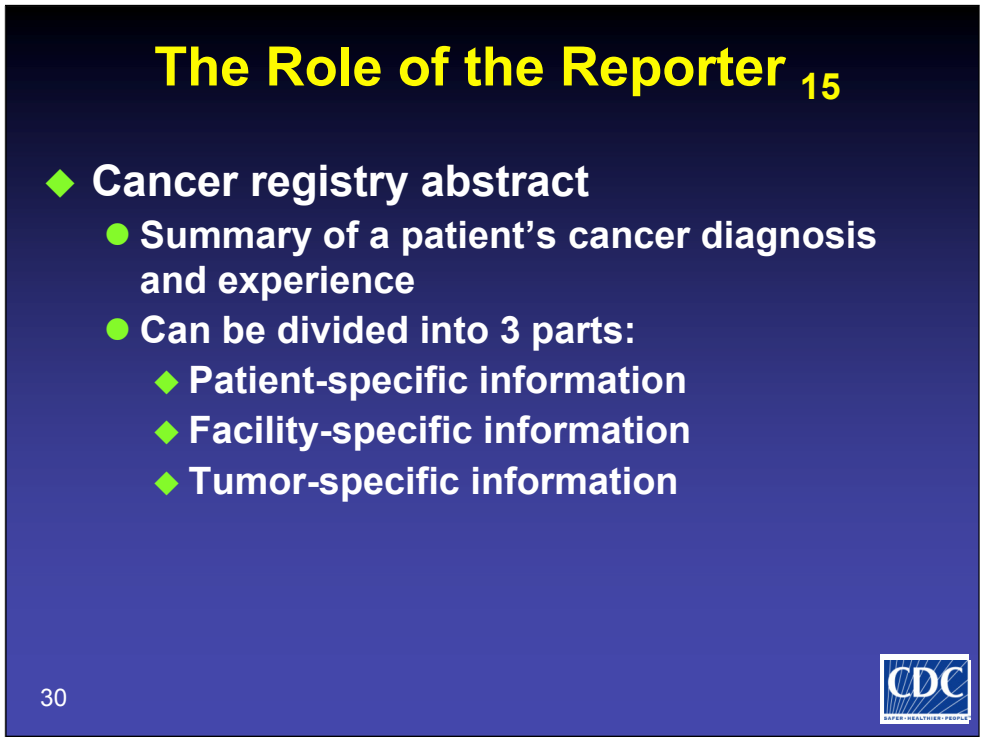


Occasionally, a patient will appear in your case finding log a second time. Determine if this is a recurrence of the original primary by using the multiple primary rules. The decision to add a new primary is not based on whether the physician says there is a recurrence; it is based on the application of the rules discussed previously. The exception is when the pathologist actually compares the current slides to the previous slides and says the current tumor is the same as the previous tumor.



If it is determined that the new case is a recurrence, do not abstract a new cancer. The recurrence of the original primary can be recorded on the original abstract for the case. The date and site of recurrence are usually noted on the abstract. The type of recurrence should also be recorded, such as whether it is local, regional, or distant.

Most central cancer registries are incidence registries and do not collect data on recurrence.



After reportable cases are identified, an abstract must be completed on each patient case.

We have discussed the format of an abstract, and now we will talk about what an abstract is. The abstract is a patient's story of his or her cancer. The abstract contains text and codes in a nationally approved and standardized format. The format of the abstract allows it to be divided into three major parts.

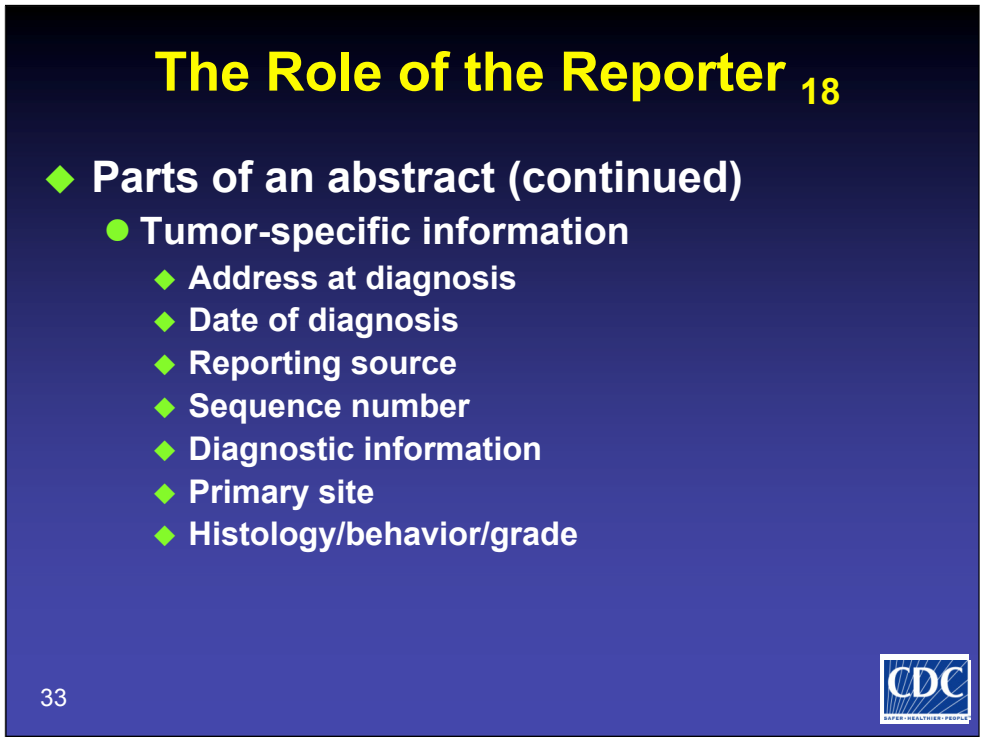
The parts of an abstract include patient-, facility-, and tumor-specific information. We will discuss each section in detail in the next section of this presentation.

Patient-specific information includes the personal identifiers for the patient. The patient may have multiple cancers in his or her lifetime, and the following information will remain unchanged.

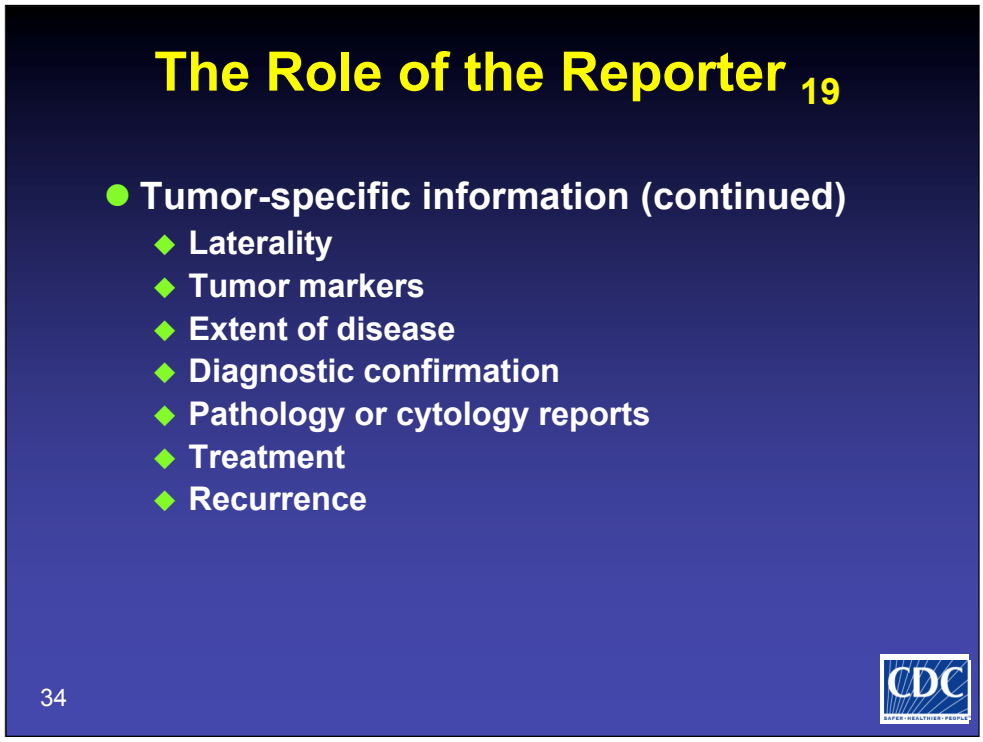
This information includes the patient's name, social security number, race, ethnicity, sex, birth date, and place of birth. The patient's current address is also included in patient-specific information, although it can change. This address may be different than the address at diagnosis if the patient moves or goes to a nursing home or hospice. Address at diagnosis will be discussed under tumor-specific information.

Facility-specific information is information specific to the facility where the patient is being seen for his or her cancer. This may be the facility where the patient was diagnosed or where he or she is being treated. This information may change with the diagnosis of a second primary. These data fields include medical record number, date of admission, date of discharge, hospital number, class of case, and medical insurance information.

The class of case distinguishes referral cases from those diagnosed at the reporting facility. It is valuable information to the reporter and is helpful to the central cancer registry when it consolidates information on cases from many facilities. Collection of the payor at time of diagnosis or insurance provider information is required if it is available.

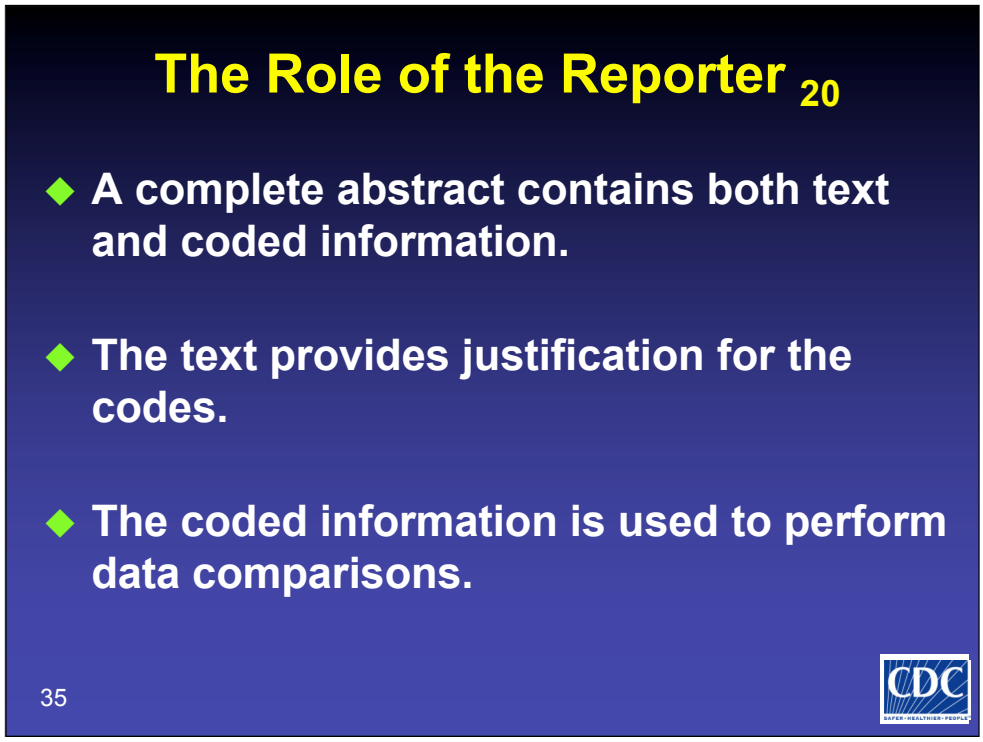


Tumor-specific information is data captured at the time of the diagnosis specific to a tumor. It includes many fields, such as address at diagnosis, date of diagnosis, reporting source, sequence number, diagnostic information, primary site, histology, behavior, and grade. If another primary tumor is diagnosed for a patient at another time, this information will be collected again for that tumor.



Other tumor-specific data include laterality, tumor markers, extent of disease, diagnostic confirmation, pathology or cytology reports, treatment, and recurrence.

All of these items help identify the specific cancer and its characteristics.



In addition to the many coded items captured by the reporter on the abstract, it is important to justify the codes selected in supporting text. Text doesn't have to be lengthy, but does need to support the coded data item. This text information is critical to central cancer registries when they need to consolidate discrepant information reported from multiple facilities.

The role of the reporter is extremely important for managing patient information and determining the accuracy of data abstracted at a facility.

To recap the types of data collected in a cancer abstract, specific information is needed on each patient.

The abstract begins with demographic data, much of which is copied directly from the medical record. This information may be located on an admissions sheet or face sheet, if provided, or on other documents within the record.

The medical history including the signs and symptoms of that patient leading to the diagnosis of cancer is needed. In other words, the history and physical examination needs to be summarized within the abstract.

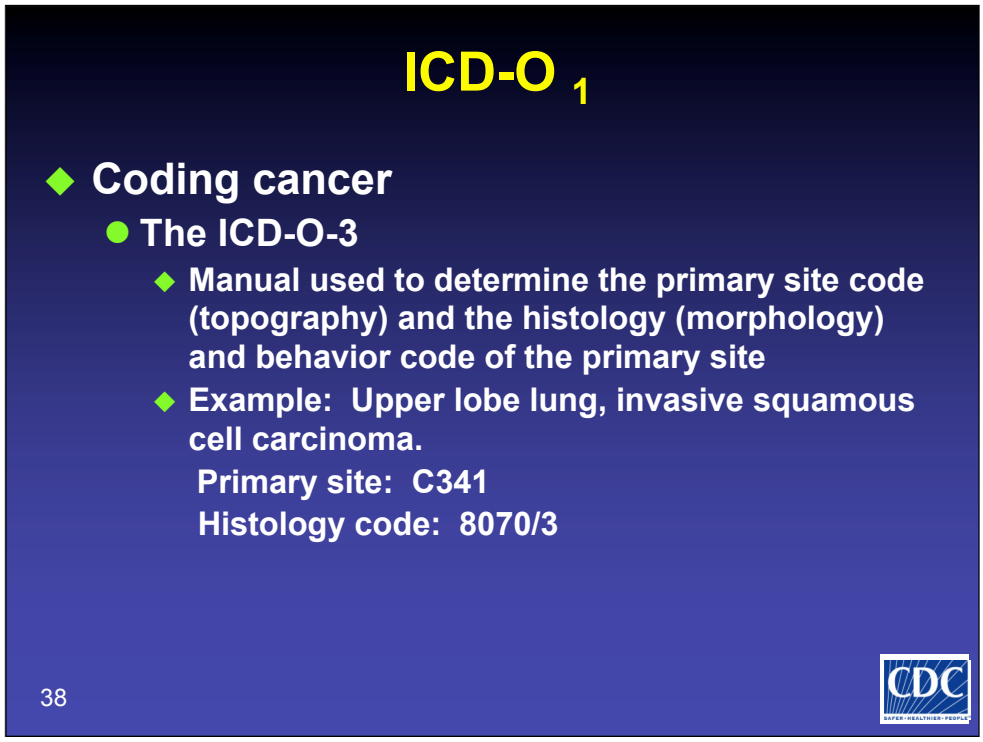
Any procedures that were performed on that patient leading to his or her diagnosis and extent of disease are recorded. X-rays, scans, laboratory work, and scopes need to be documented. This includes negative exams that may rule out cancer spread. There are very specific coding rules for each cancer site for capturing extent of disease information.

The therapies used to treat the cancer are also documented using specific codes. If the patient has surgery, chemotherapy, radiation therapy, or any other treatment modalities, they are recorded within the abstract. Any outpatient therapies given to the patient for which documentation is available should be recorded also.

How to collect the details of each of these sections will be discussed shortly.

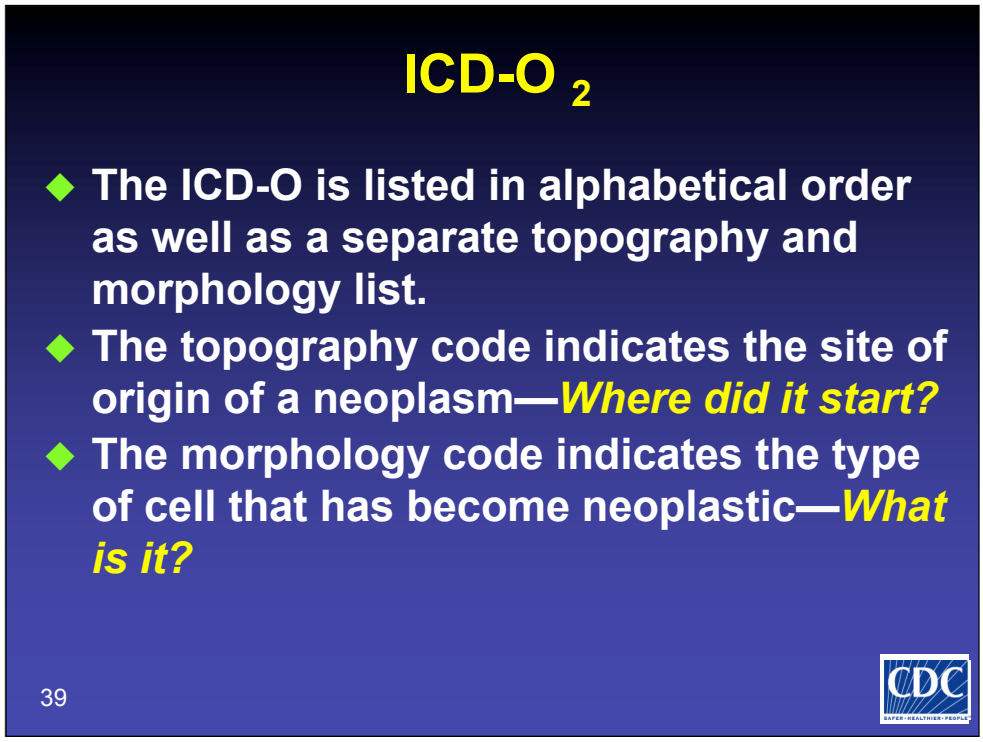
The length of disease-free survival is measured by comparing the date of diagnosis to the date of recurrence. That is why the date of first recurrence is recorded, as well as the type of recurrence. This gives an indication about the success of various types of treatments in treating specific cancers. Research protocols are built around disease-free survival trends.

It is important to capture combination therapies. For instance, combining chemotherapy and radiation therapy in the treatment of some cancers has proven successful, while surgery followed by radiation or chemotherapy is better for other types of cancers. Success is measured by longer periods of disease-free survival.



The official reference manual for coding cancers is the most current edition of the *International Classification of Diseases for Oncology,* usually referred to as ICD-O. This coding scheme has two parts: topography or primary site, and the histology or morphology.

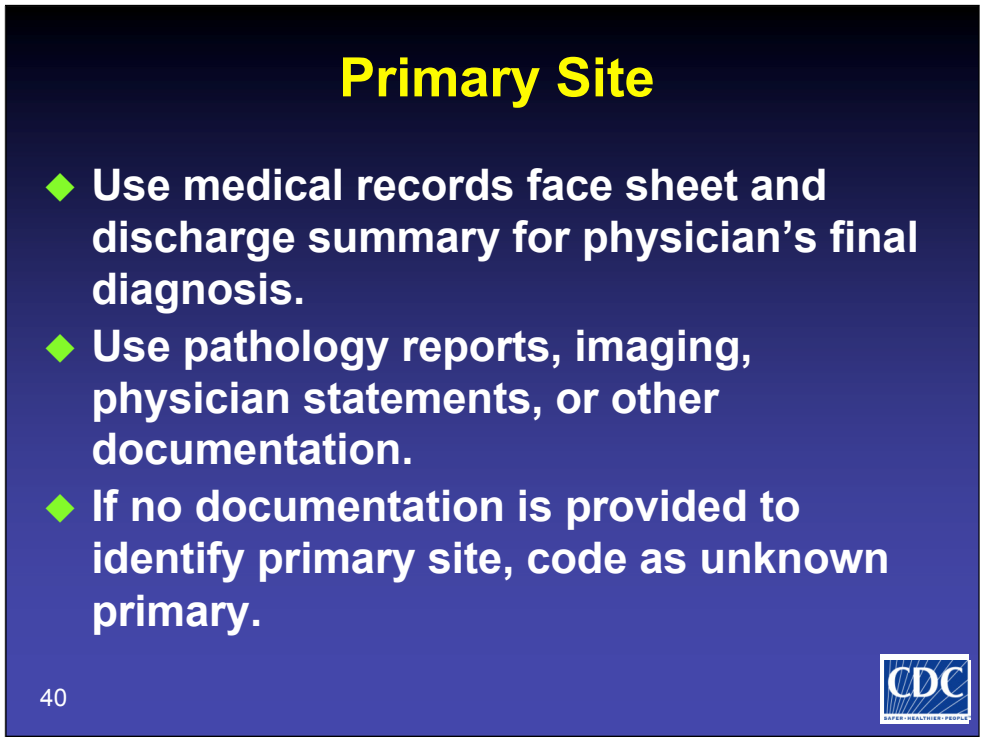
ICD-O contains coding instructions at the front of the book. These rules need to be read and understood before coding primary site and morphology. The rules should also be referred to any time you have a coding question.



All of the terms in the ICD-O are listed two ways: alphabetically at the back of the book, and in numeric order toward the front of the book after the coding instructions. New reporters may find it easier to use the alphabetic index for histology coding.

To code the topography or site of origin, the reporter must determine where the cancer started. That organ is the primary site. The organ name should be looked up in the index and the code associated with it recorded on the abstract. In the previous example, the cancer started in the upper lobe of the lung. Look up “lung, upper lobe” and write down code C34.1.

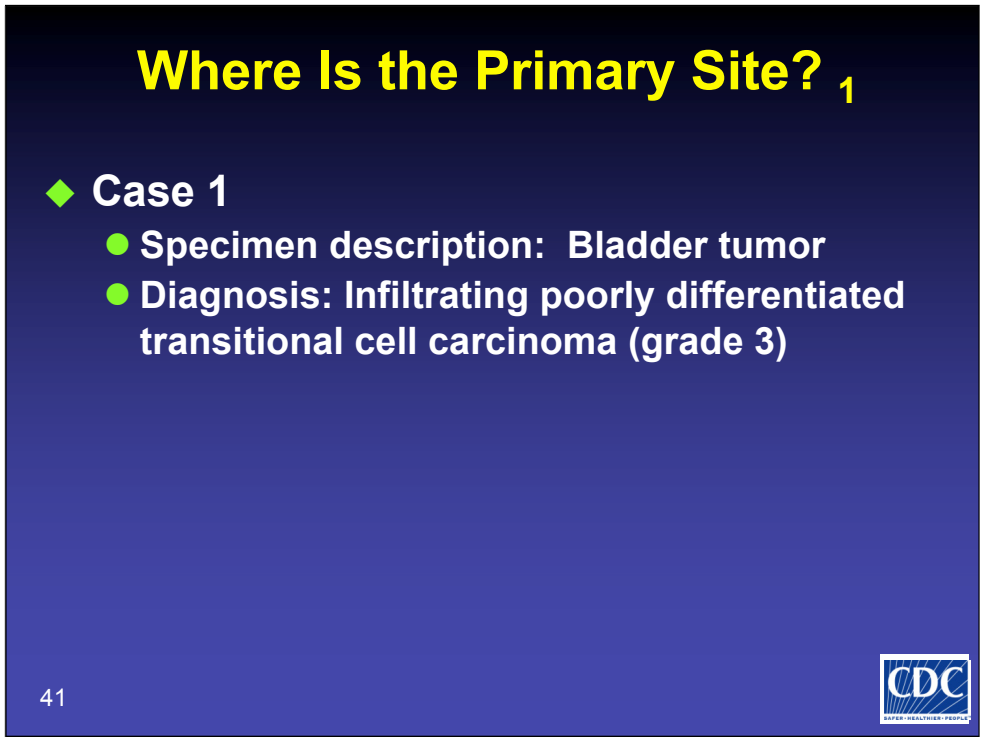
To code the morphology or cell type, the kind of cancer, or its name, must be determined. This term is the histology or morphology. Look up these words in the index and write down the code associated with them. In the previous example, the kind of cancer is “squamous cell carcinoma.” When squamous or carcinoma is reported, find the code that includes all three words this is the code. In this case the code is 8070/3. The 3 indicates that the tumor is invasive, as we will discuss later.



To determine what the primary site is, available documentation must be read thoroughly. Medical records usually include a face sheet that reports a final diagnosis provided by the attending physician. This usually includes the primary site of the cancer. Medical records also include a discharge summary report that is completed by a physician and includes a final diagnosis.

If a pathology report is the only documentation available, the type of tissue that was removed will help determine the primary site. If a radiation therapy summary is provided, it will usually mention of the primary site, and it may be the field that is treated. If a surgery report is present, it may be the organ that is operated on. Many times reports contain a final diagnosis that will indicate the primary site. X-rays and scans can also be good sources for descriptions of the primary site.

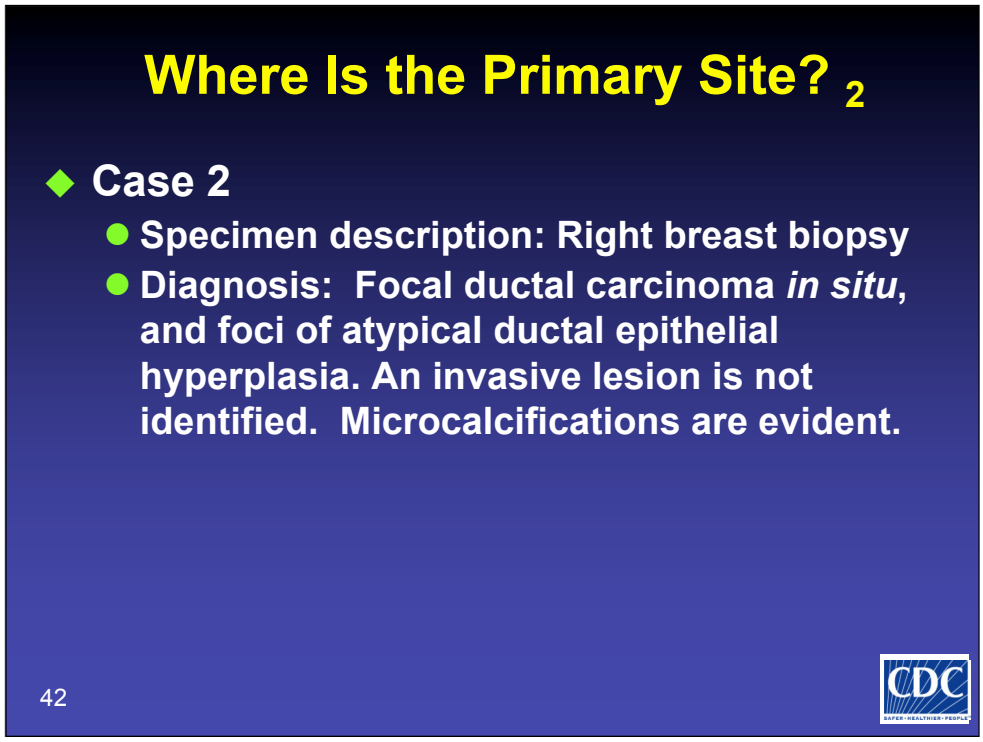
Occasionally the report(s) available give no indication of the primary site. In such cases, the primary site is unknown, and there is a code for that in ICD-O.



We are going to review several cases. You may want to look these up in your ICD-O book as we go along.

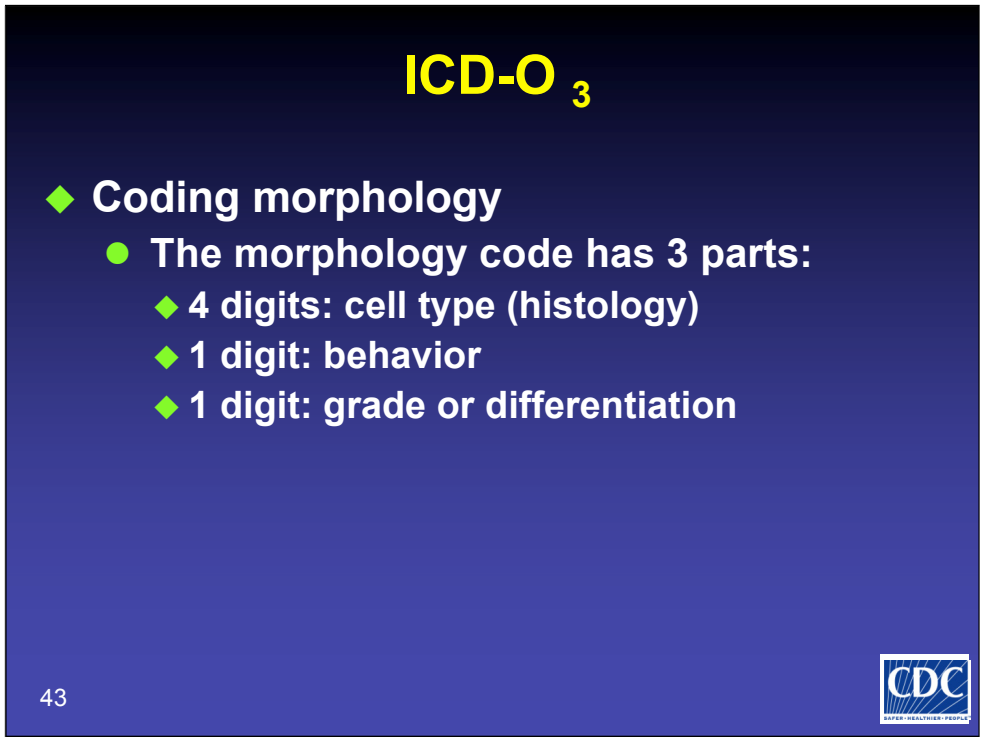
Here's an example of information from a pathology report. The final diagnosis identifies the tissue that was removed as the bladder. When "bladder" is found in the ICD-O index, several codes are listed for various areas within the bladder, but in this case, the area of the bladder is not specified. The primary site is coded to C679, Bladder not otherwise specified (NOS).

The primary site code for this case is C67.9 Bladder NOS.

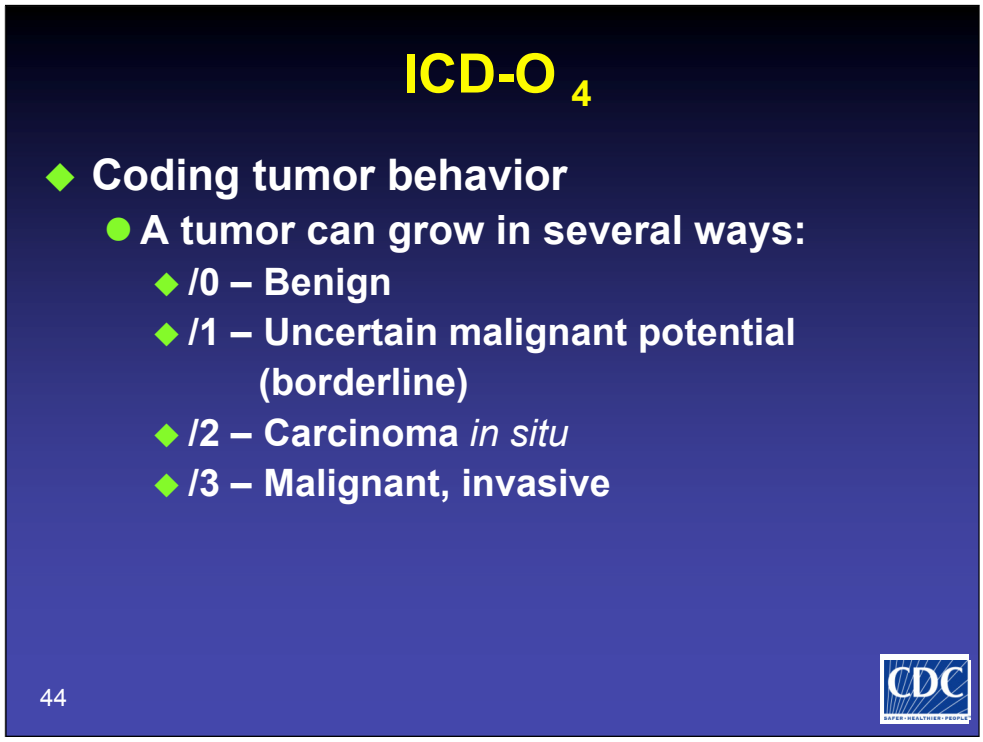


In this example, the specimen is a breast biopsy. Again, the specific area of the breast in which the tumor arose is not identified. When "breast" is found in the ICD-O index, the non-specific breast code is at the top of the list. This case is coded to Breast not otherwise specified (NOS).

The primary site code for this case is C50.9, Breast NOS.



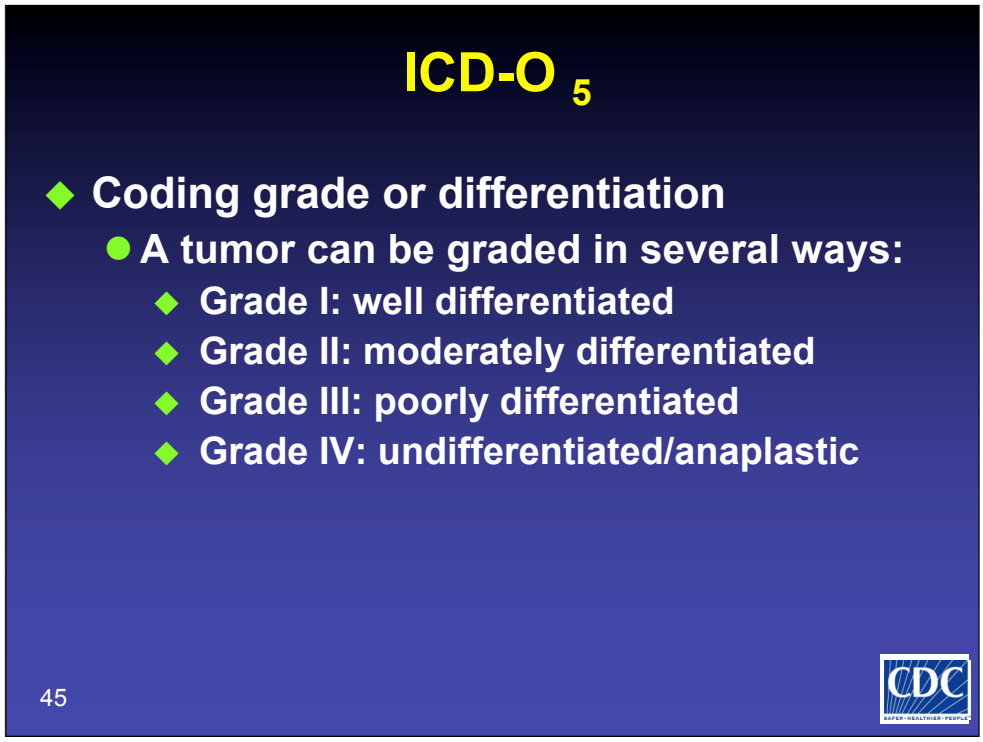
The morphology code actually consists of three parts. We have talked about the morphology or histology of a tumor. The behavior of a tumor is the way it acts within the body. The grade or differentiation provides additional information about the tumor. It describes how closely the cancer cells resemble normal tissue.



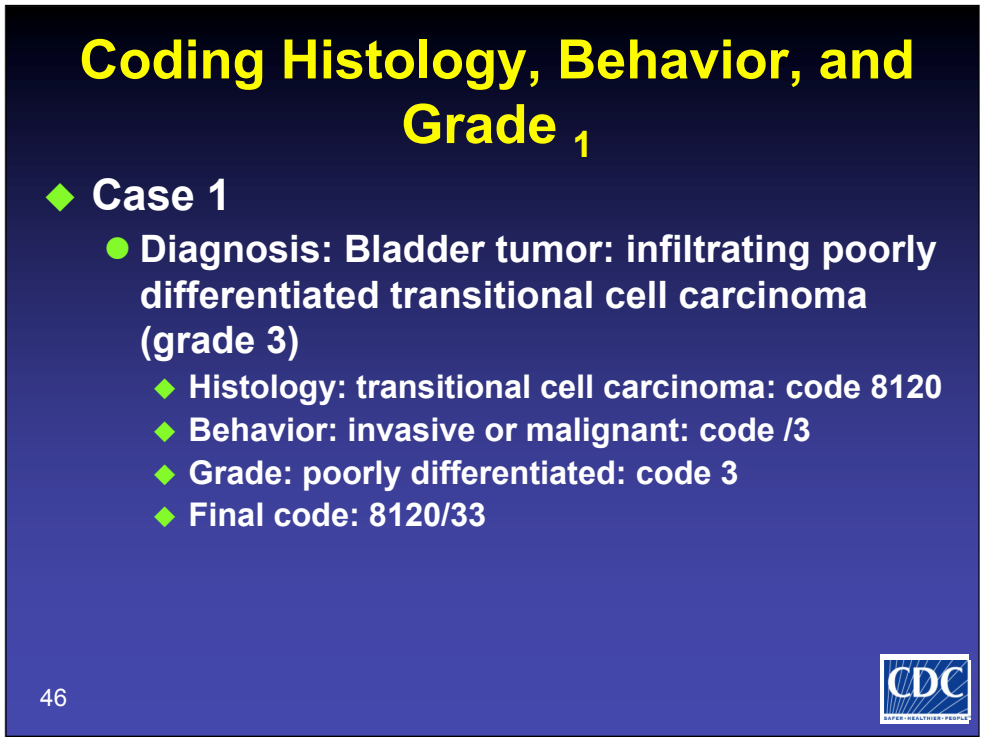
The fifth digit of the histology code is the behavior code. This describes how the tumor grows. Some tumors stay in one place and don't spread. These are referred to as benign tumors and are coded /0.

Other tumors are malignant. Tumors that have all the characteristics of malignancy except invasion are called carcinoma in situ and are coded as /2. The ones that have invasive qualities are /3, malignant and invasive. Sometimes pathologists cannot tell how a tumor is going to behave, and refer to them as uncertain malignant potential or borderline tumors. These are coded /1.

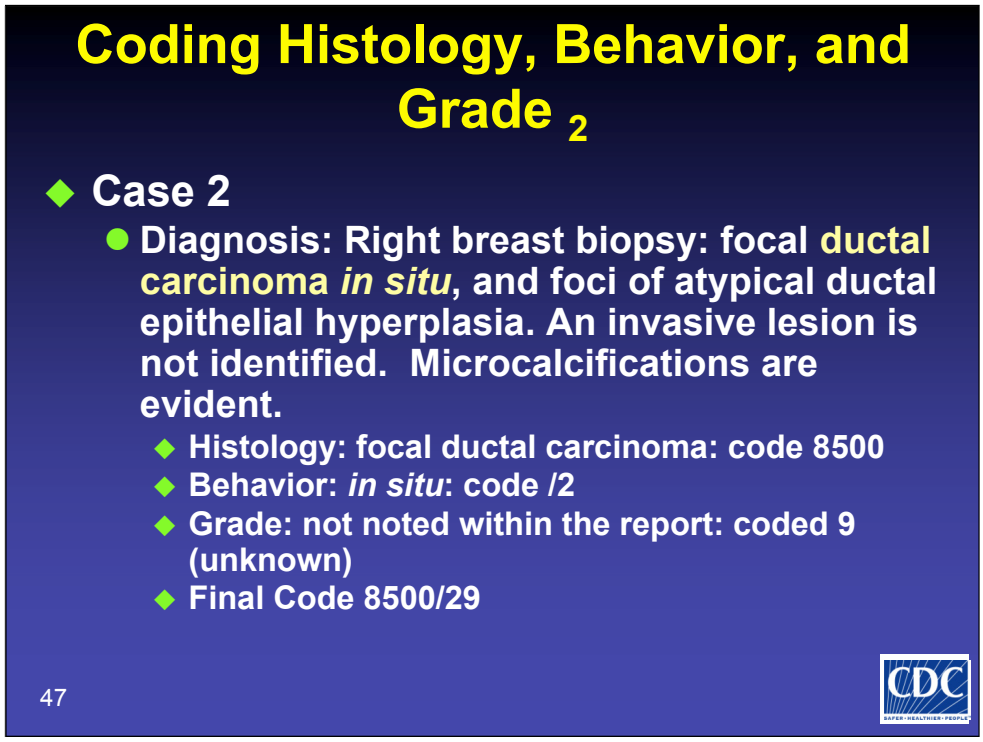
Central cancer registries collect malignant (/3) tumors of all organs, in situ (/2) tumors of all organs except the cervix, and benign (/0) and borderline (/1) tumors of the central nervous system.



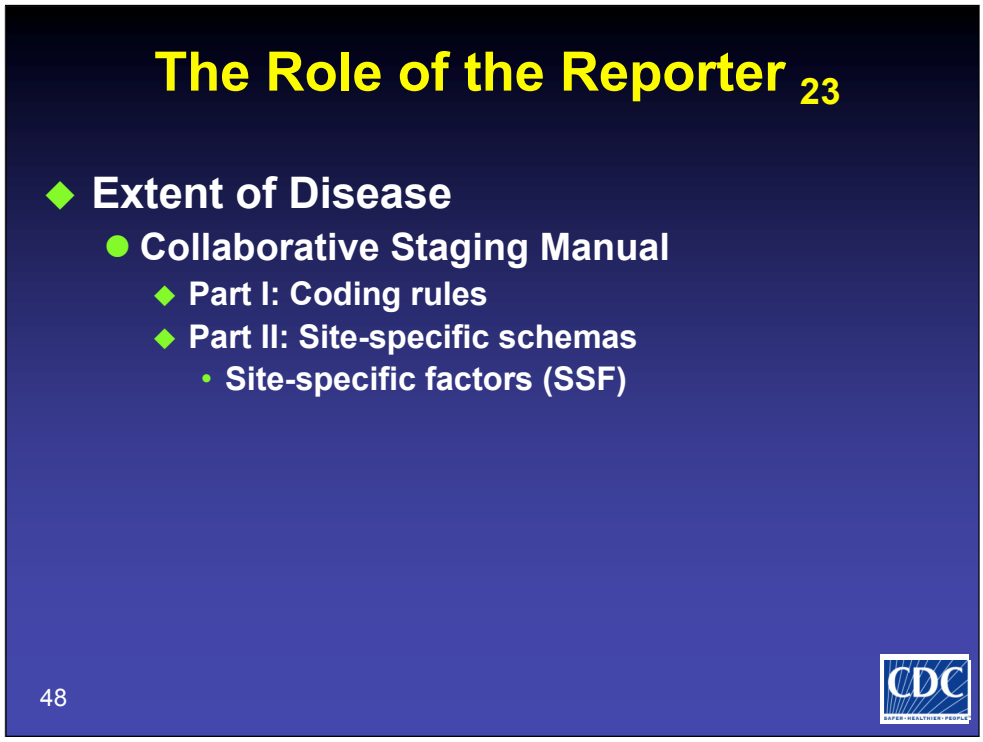
The grade of a tumor represents how aggressive the cancer is. Most cancers are graded on a scale of 1 (least aggressive) to 4 (extremely aggressive). These may also be referred to as well-, moderately-, poorly-, or un-differentiated. Some cancer sites use other scales that can be converted to codes 1 through 4. Your registry coding manuals will provide information on those.



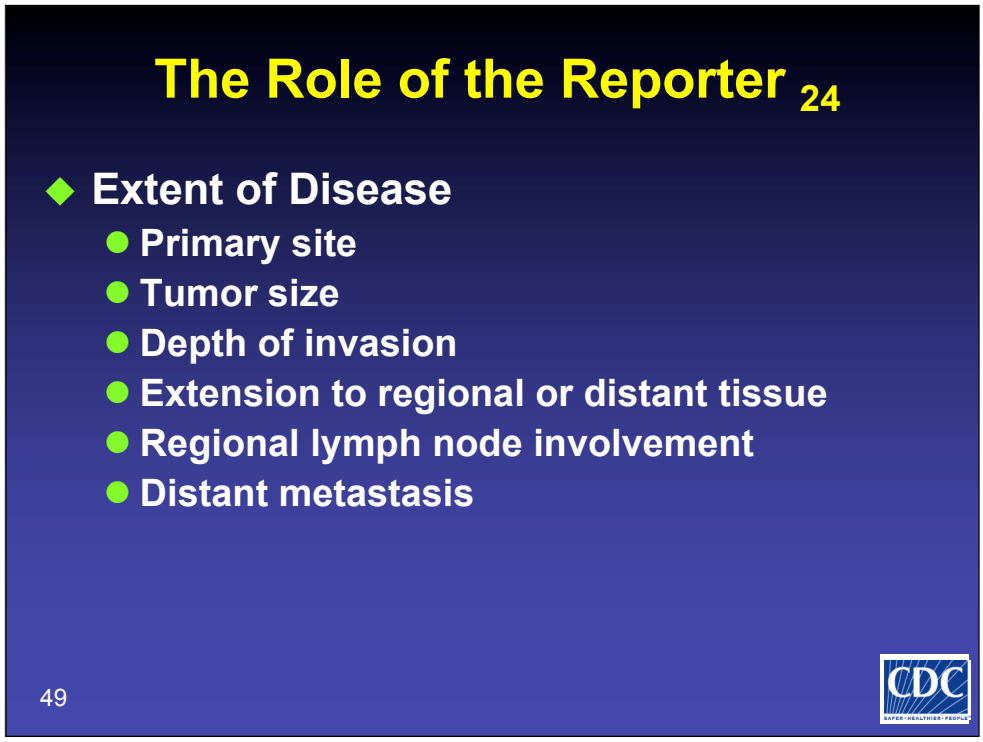
This is information from the Case 1 pathology report again. It is a transitional cell carcinoma. "Transitional cell carcinoma" and "carcinoma, transitional cell" are both listed in the ICD-O with the same code, 8120. The tumor is described as infiltrating or invasive, which is behavior code /3, and the grade is “poorly differentiated” which is a code 3 in the sixth-digit position.



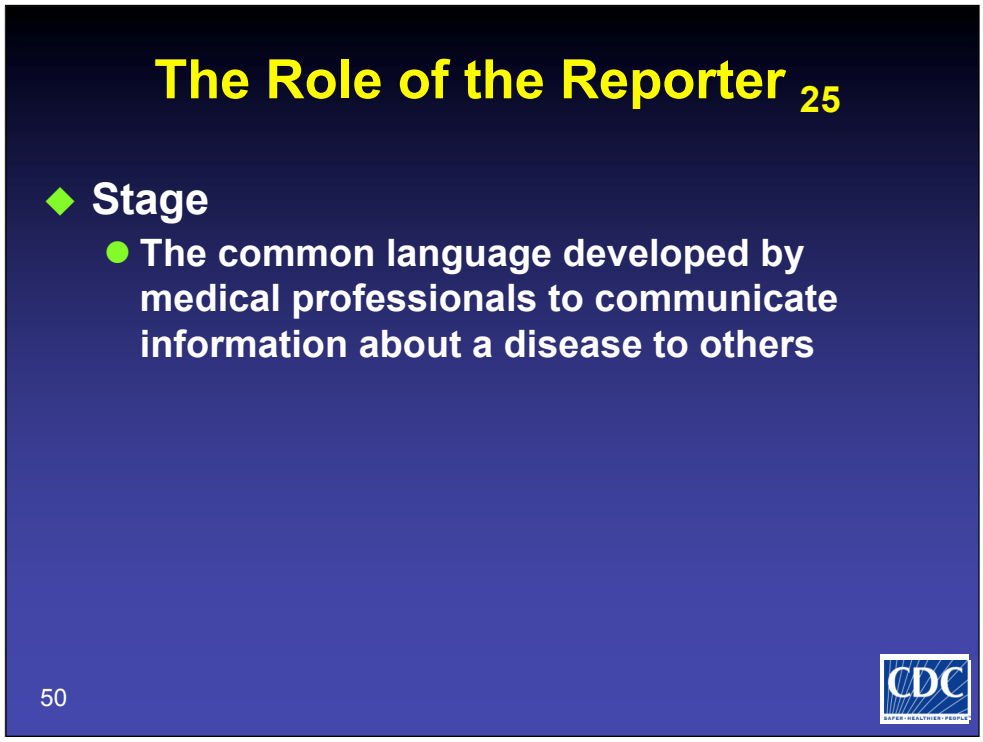
Here is the Case 2 diagnosis again. It contains some extra terminology. The key words are “ductal carcinoma” and “*in situ*.” Atypical ductal epithelial hyperplasia is not a cancer diagnosis, nor are micro-calcifications. When “Ductal carcinoma” or “Carcinoma, ductal” is found in the alphabetical index of the ICD-O, the list of terms contains “Ductal carcinoma *in situ*,” which is 8500/2. A grade or degree of differentiation is not mentioned, so ICD-O rules say to code the grade (sixth digit) as unknown.



When the primary site, histology, and behavior are determined, the extent of disease can be coded. This is done using the Collaborative Staging (CS) Manual. The CS manual is a manual containing site-specific extent of disease codes. Each code represents a specific extent of invasion by the tumor from the site of origin. Part I of the CS manual describes the coding rules in detail. Part II lists each primary site and the extent of disease codes appropriate to that site. Site-specific factors (SSF) are included within some site-specific schemas. We will focus on the SSF required by the National Program of Cancer Registries (NPCR).



When evaluating the extent of disease, these elements should be considered. Each element has a specific set of codes within the CS manual. After these elements are coded appropriately, the computer algorithm in the cancer registry software will produce a stage.



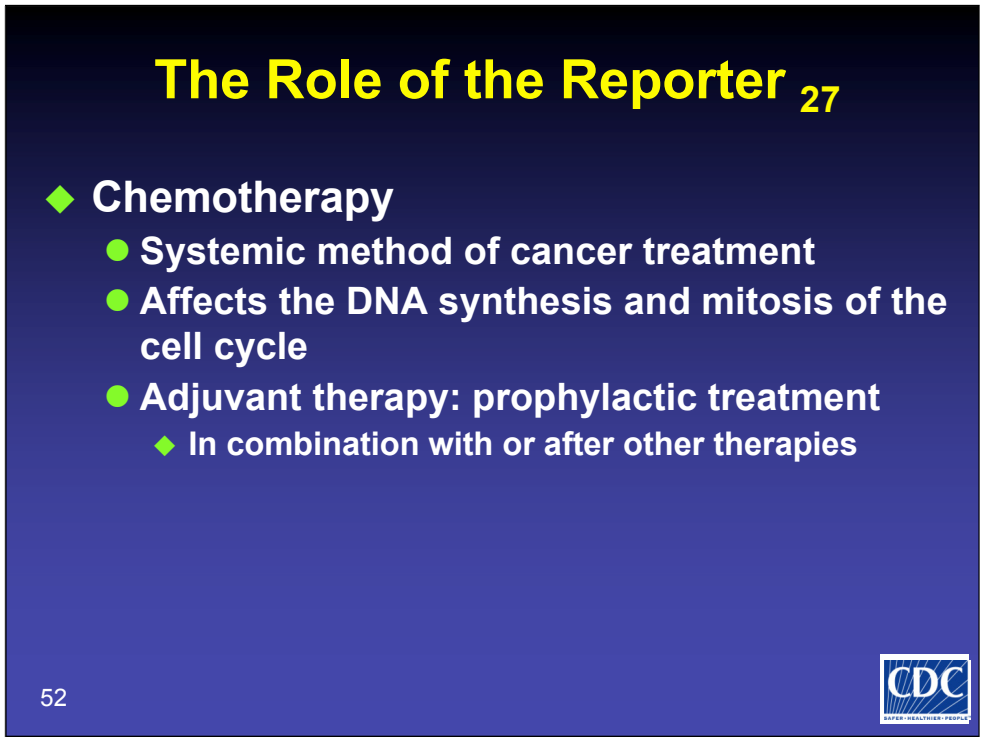
"Stage" describes how far the cancer had spread at the time. It is a way to summarize the extent of disease into clinically useful categories. Staging is a type of medical shorthand that conveys information among health professionals about tumor involvement and relative prognosis.

*Source: CoC *Standards of Commission on Cancer Vol. II: Registry Operations and Standards.*

The first course of treatment for cancer is based on the cancer patient's stage at diagnosis. The first course of treatment for cancer can vary depending on primary site. You must know and understand what primary cancer is being treated to be able to complete an abstract. The therapy given to a patient will depend on the stage or extent of disease of the cancer. Sometimes it can be difficult to determine what the first course of therapy includes. Any type of cancer can have a number of different combinations of therapy.

First course therapy is any therapy that is given and/or planned at the time of initial diagnosis. For instance, a primary breast cancer that is localized will be likely to undergo a lumpectomy of the tumor followed by radiation therapy to the breast and possibly the regional lymph nodes. If the tumor is ER positive, the patient may also be offered hormonal therapy.

Your data collection manual or FORDS provides codes for each type of treatment.



Chemotherapy is often given as a first line agent for cancer control. Most chemotherapies affect and destroy actively dividing cells by disrupting the DNA syntheses and the mitosis of the cell cycle. Chemotherapy can be given in combination with other therapies, such as surgery or radiation therapy. Many times the combination of drugs and other treatments has proven to be more effective in control of cancer than a single type of treatment. However, sometimes a patient may not be able to tolerate a certain type of chemotherapy. If the physician changes the chemotherapy to a different agent within the same category as the original drug, it is still recorded as initial treatment.

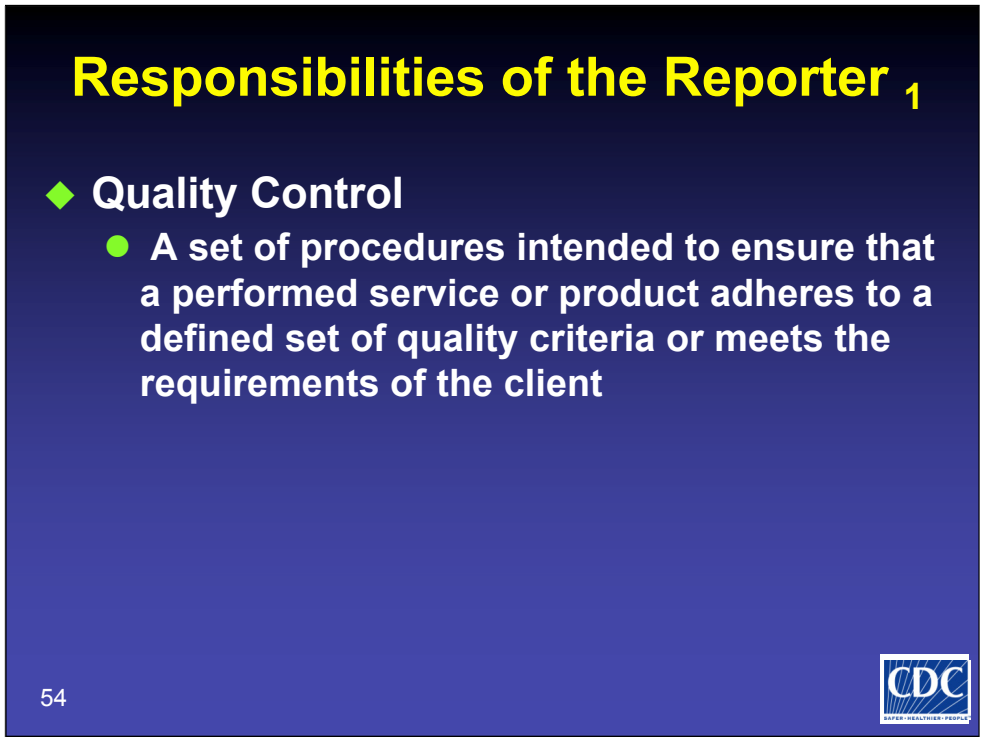
Adjuvant therapy is *prophylactic* treatment of areas of potential microscopic spread in the hope of preventing or delaying recurrence and prolonging survival. It is given *in conjunction with* or *after* other methods have destroyed the clinically detectable cancer cells.

The term is usually interpreted as chemotherapy, although radiation therapy can also be adjuvant in nature.

There are several types of chemotherapy agents. For example, akylating agents include cytoxan and melphalan.

Antimetabolites are methotrexate and 5-FU. Antitumor antibiotics include adriamycin and bleomycin. Alkaloids include vincristine and miscellaneous agents include cisplatin and VP-16.

The National Cancer Institute's SEER program provides a free cancer registrars' interactive antineoplastic drug database to look up drugs and their types. This database lists the category, generic name, and brand names of agents, as well as other pertinent information such as the primary cancers against which a particular drug is effective.



When the demographic, cancer identification, extent of disease, and treatment information have been entered into the abstract, you are almost finished with abstracting. The final step is to perform quality control on the information in the abstract before you send it to the central cancer registry (CCR).

The technical definition of quality control is a set of procedures to ensure that something, in this case your abstract, meets the requirements of the client, in this case, the reporting facility and the CCR.

Responsibilities of the Reporter 2

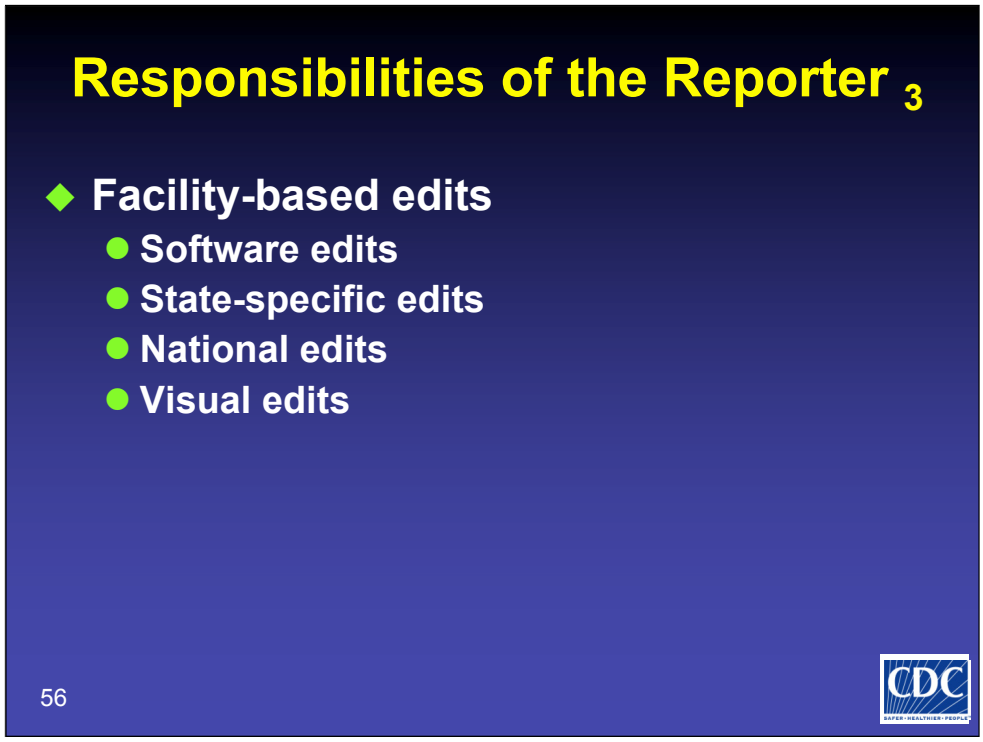
- Quality through monitoring of data
  - Check the data
  - Identify any problems in the data
  - Fix the problems in the data

55

Quality control can be most effective if an appropriate measure is selected. Most registry software used to report cancer data provides certain measures to assure quality, called "edit checks." For example, all prostate patients must be coded to the sex of male. If the quality control checks find a prostate cancer patient is coded to the sex of female, this must be corrected before the case is saved and marked as ready to be submitted to the central cancer registry (CCR).

Some edit checks can be set with an override. This means a warning is generated, but the reporter can indicate, after review, that the information is correct. For example, a 35 year-old male has prostate cancer. It is very unusual for a man this young to have prostate cancer, so the software warns the reporter this is an unusual occurrence. The reporter should note this in a text field for clarification when the CCR sees it.

When you are sure the information in the abstract is as accurate as it can be, it is ready to be sent to the CCR.



The reporter can perform several types of edits on the cancer data collected.

Most cancer registry software programs will run specific edits on the cancer abstract. Any edit issues identified need to be corrected before the data are submitted to the central cancer registry (CCR). State-specific and national edits are usually programmed within the software and can be run in batch edits or on individual cases. Software edits can also be created by the reporter. The reporter and/or facility should develop a routine for handling edits and performing edit checks. The reporter should ensure all of the edit checks to which their data will be subjected at the CCR are incorporated in their software. It is a lot easier and more efficient to correct errors when the medical records are available as reference, than to have to obtain them again later to check or correct errors identified by the CCR.

Visual editing is a more detailed process, but even new reporters can do it. To do a visual review of an abstract, select a cancer site and compare data elements. A good example of a visual edit is looking at cervical cancer and sex. If any cervical cancers aer coded to males, you need to review the abstracts. The same is true for prostate cancer and females. Other types of visual edits are to compare the name and sex, age and primary site, stage and treatment, and city and county. Most of these types of edits are conducted by experienced quality control staff at the CCR, and they should let the reporter know if they have changed anything and what specifically they changed and why.

Central cancer registries (CCRs) have their own policies and procedures for quality control. Most CCRs review a percentage of abstracts submitted by reporting facilities, especially abstracts submitted by new reporters. Another means of quality control by CCRs is looking at ongoing processes, such as timeliness of reporting, which can trigger a review when processes exceed the established limits. Most CCRs will conduct studies designed to look at numerous measures of quality.

Reabstracting studies are an example of checking the accuracy of data submitted in the original abstract. In this type of study, CCR staff compare the abstracted information to the medical record. Recoding of the abstract by CCR staff can also be performed and measured against the original abstract.

If the CCR finds any problems with the abstracted information, they will contact the reporter and let him or her know what has been found so it can be justified or corrected. This outside review of abstracts is an important part of the learning process for new reporters.

In the next part of this presentation, you will actually see how an abstract is completed.